Facilitating family support when a parent of dependent children is at end of life

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I confirm that the word count for this thesis is less than 40,000 words

Dedicated to

Professor. Eilís McCaughan

CONTENTS

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ABSTRACT

Introduction

Preparing dependent children for the death of a parent is one of the greatest challenges faced by parents when mum or dad is at end of life from cancer. Parents are often uncertain if, how, when they should prepare their children for the inevitable death of mum or dad. Parents often feel it is protecting their children by not telling them mum or dad is eventually going to die from cancer. Children less prepared for the death of a parent are more susceptive to poorer psychosocial adjustment in later life. Parents often require supportive guidance from health and social care professionals surrounding how best to prepare their children for the death of a parent. However, it is not clear what is provided in routine practice. This study aimed to explore how parents can be best supported, when a parent with cancer is at end of life (EOL) and has dependent children.

Methods

Following a systematic review addressing challenges and support needs of parents and children when a parent with cancer is at EOL, an interpretative qualitative study was conducted using semi-structured interviews. Four sample groups were included in this qualitative study. This included parents at EOL *(n3),* bereaved parents *(n21),* health and social care professionals *(n32)* and funeral directors *(n23).* Data was analysed using thematic analysis, guided by Braun and Clarke's six step approach.

Results

Findings highlighted the intricate challenges experienced by parents, as they prepare their children for the death of mum or dad. Key obstacles to preparing the children for the death of mum or dad included parents emotional readiness to telling them the reality of the situation, opposing parental beliefs surrounding how best to support the children when mum or dad was at EOL from cancer, and parents hope of living longer. The provision of supportive care towards parents at EOL concerning their children was often considered by most health and social care professionals as 'not my role'. In the absence of supportive care to parents at EOL, parents sought guidance from the funeral director, surrounding how best to support the children in the acute post death period once the parent had died. Funeral directors

can have an instrumental role in guiding parents through the distressing immediate bereavement period.

Conclusions

A number of recommendations are reported, that may help facilitate a better experience for parents of dependent children when mum or dad is at EOL from cancer. Key factors include a need for clear prognostic information from health and social care professionals surrounding the reality of the parent's declining health, guidance from professionals concerning how to tell the children mum or dad is eventually going to die from cancer, and the need for parents to advance plan for the future before the parent dies. There appears to be a disparity between health and social care professionals having an awareness of the needs of parents at EOL concerning their children, and the provision of supportive care in routine practice. There is a need for health and social care professionals to recognise their pivotal role in the provision of supportive care to parents concerning their children, when mum or dad is at EOL from cancer. Policy guidelines and training should be developed for health and social care professionals and funeral directors to incorporate these appropriate aspects of care into their role.

Key words: parents, parental cancer, children, qualitative research, end of life, dying, health professionals, funeral directors

DECLARATION

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LIST OF PUBLICATIONS AND STATEMENT OF THE PHD STUDENT'S CONTRIBUTIONS

Paper 1 (Published)

Hanna, J. R., McCaughan, E., & Semple, C. J. (2019). Challenges and support needs of parents and children when a parent is at end of life: A systematic review. *Palliative Medicine*, *33*(8), 1017-1044. https://doi.org/*10.1177/0269216319857622*

PhD researcher's contribution: First and corresponding author. Developed the search strategy and conducted the search. Critically appraised included studies. Coded data and identified and synthesised themes. Drafted and compiled the manuscript. Revised the manuscript based on co-authors comments. Submitted the manuscript to the journal. Revised the manuscript and resubmitted to journal based on reviewers comments. Managed the review process.

Paper 2 (Submitted for peer-review)

Semple, C.J., McCaughan, E., Beck, E.R., & **Hanna, J.R.** 'Living in parallel worlds' - Bereaved parents' experience of family life when a parent of dependent children is at end of life from cancer. *Palliative Medicine*

PhD researcher's contribution: Co-developed the study alongside the research team and study's expert group. Sole responsibility of recruitment of participants to the study. Co-facilitated data collection alongside the first author. Co-involved in study analysis and production of manuscript.

Paper 3 (Published)

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PhD researcher's contribution: First and corresponding author. Co-developed the study alongside the research team and study's expert group. Co-recruited participants to the study.

Sole-responsibility for data collection. Conducted study analysis and produced manuscript. Revised manuscript based on co-authors suggestions and feedback. Submitted manuscript to journal and managed the submission process.

Paper 4 (Published)

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PhD researcher's contribution: First and corresponding author. Co-developed the study alongside the supervisory team and study's expert group. Recruited participants and conducted data collected and analysis. Drafted manuscript, and revised manuscript based on co-authors suggestions and feedback. Submitted manuscript to journal, revised and resubmitted manuscript according to peer-review and editorial comments. Managed the review process.

CHAPTER ONE: INTRODUCTION

1.1 Introduction and study context

In the United Kingdom (UK), over 350,000 cases of cancer were reported in 2016, of which 28% resulted in death (CRUK, 2016). While specific parental-cancer mortality rates are not available, in the UK it was estimated that 23,600 parents died in 2015, leaving an estimated 41,000 dependent children (<18 years old, Child Bereavement Network, 2016). It is estimated that 5% of children living in the UK will experience the death of a parent before the age of 16 (Child Bereavement Network, 2016; Parsons, 2011).

By the time a parent has been informed that their cancer is end-stage, often the parents have been living with the cancer and its effects on their family for many months or often years. Literature has documented the needs of parents and children when a parent has been diagnosed with cancer (Helseth & Ulfsaet, 2005; Semple & McCance, 2010; Semple & McCaughan, 2013). On occasions, a parent may receive a poor prognosis at diagnosis, and the parents have less time to deal with its effects on their family.

One of the greatest challenges faced by parents is how best to prepare and support their children throughout the end of life (EOL) cancer experience (Beale et al., 2004; Bugge et al., 2009; Fearnley & Boland, 2017). Parents often delay telling the children that their mum or dad is going to die from cancer to protect them from pain and upset (Buchwald et al., 2012; Kopchak-Sheehan et al., 2014; MacPherson, 2005). Alongside this, parents are often uncertain how to communicate information with their children throughout the emotional EOL period surrounding the ill-parent's impending death (Bugge et al., 2009) and actual death (Sheehan et al., 2019). Children less prepared for the death of a parent are more susceptive to adverse psychological adjustment in later life (Ellis et al., 2013). This is compared to children who are informed of their parent's declining health and included in aspects of the ill-parent's care at EOL (Abdelnoor & Hollins, 2004; Berg et al., 2014; Ellis, 2013; Forrest et al., 2006; Visser et al., 2004). There is a

need for parents to be encouraged to foster an environment of open communication with their children, and involve them throughout the EOL experience when a parent is dying from cancer.

To help facilitate positive coping for most children when a parent is at EOL from cancer, it is necessary to ensure parents feel supported so they can prepare the children for the impending death of their mum or dad. This PhD study aims to better understand how parents could be best supported throughout the EOL experience when a parent is dying from cancer. The rationale for the study is now discussed.

1.2 Rationale

Preparing dependent children for the death of mum or dad to cancer is a stressful period for parents (Lundquist, 2017). Factors contributing towards parents' distress and concern include how best to manage the EOL experience with their children (Fearnley & Boland, 2019), and telling them mum or dad is going to die (Kopchak-Sheehan et al., 2014). However, literature has predominately reported what promotes a more positive experience for parents at EOL, such as having internal and external social networks to provide practical support (Bugge et al., 2008; 2009; Kennedy et al., 2008; Park et al., 2017), and meeting other parents at family support services who are experiencing a similar situation to them (Lundquist, 2017; Turner et al., 2007). This is not likely a complete reflection of the experiences for many families when a parent is dying from cancer. There is a gap in the literature surrounding how parents navigate the EOL experience alongside their children. This knowledge may aid our understanding concerning if, how and when support can be facilitated to parents throughout the EOL experience.

Alongside this, existing literature lacks detail surrounding how the needs of parents can be best supported, as they support their children for the death of a parent. For example, parents have been reported to find it helpful when they were provided with appropriate language as they prepared to tell the children that mum or dad was going to die from cancer (Bugge et al., 2009; MacPherson & Emeleus, 2007), however it is unclear what this helpful language looked liked. A better understanding of the requirements for parents at EOL in relation to the children may offer

insight as to how and when specific support is required, and who is best placed to provide such care to parents, as they support their children for the death of mum or dad. Empowering parents to support the children throughout the EOL period may help mediate adverse psychological outcomes, and promote a more positive coping experience and resilience for the children into their adult life (Ellis, 2013; Ellis et al., 2017).

The majority of studies that have explored the needs of parents of dependent children when mum or dad is at EOL from cancer are representative of middle-class families attending support groups, and have direct supportive involvement from a family support worker (Alvariza et al., 2017; Bugge et al., 2008; 2009; 2014; Kennedy & Lloyd-Williams, 2009a; 2009b; Park et al., 2017). Studies have stated that as a result of engagement with support groups, professionals and workers within these organisations are often having difficult conversations with the children, such as sharing the news with them that their parent is eventually going to die from cancer (Clipsham et al., 2015; Punziano et al., 2017; Turner et al., 2007). It is not clear how parents manage challenging conversations with their children surrounding the ill-parent's declining health in the absence of this support. Also, family support services are limited and the majority of families within this population do not have access to, or avail of them (Cecil et al., 2010; O'Neill et al., 2013). Exploration of the needs of parents, to include those who do not typically avail of support groups, such as men (fathers), and families from low socioeconomic status communities and educated backgrounds (Arber & Odelius, 2018; Grande et al., 2006; Steginga et al., 2008) will provide a better representation of the needs of parents, when one of them is at EOL.

Parents often seek help and guidance from health and social care professionals (HSCPs) concerning how to prepare their children for the death of a parent (Fearnley & Boland, 2019; Franklin et al., 2019). HSCPs are well-placed to provide psychological care and support to parents, when a parent is at EOL from cancer. The United Kingdom policy for EOL care includes commitment to psychosocial support for patients and their families (Abel & Kellehear, 2016). However, there are currently no mandatory guidelines or training available to support HSCPs' provision of supportive care to parents at EOL regarding their children (Department of Health,

Social Services and Public Safety, 2010; Franklin et al., 2019; National Palliative and End of Life Care Partnership, 2018; NICE, 2014), and family-centred care can often be inadequate in routine practice (Arber & Odelius, 2018; Franklin et al., 2019; Fearnley & Boland, 2017; Karidar et al., 2016). Exploration of the experiences and perceptions of caring for parents of dependent children when one of them is dying from cancer, from a range of HSCPs involved in EOL care, may aid our understanding surrounding how HSCPs can be equipped to provide support to parents at EOL regarding the children. This knowledge could inform the development of evidenced-based training resources for HSCPs, to support their provision of providing supportive care to parents concerning the children when mum or dad is dying from cancer. Ultimately, this could empower parents to support the children pre-bereavement and build resilience for their child's future (Ellis et al., 2017).

In light of the aforementioned rationale the current study was considered necessary and important, as it has the potential to significantly contribute to the literature concerning the needs of parents, when a parent of dependent children is at EOL, and help facilitate a better experience for future parents, as they prepare their children for the death of mum or dad from cancer. The aims and objectives of the study are presented below:

1.3 Research aims and objectives

Aims

To explore how parents can be best supported, when a parent with cancer is at EOL and has dependent children.

Objectives

- to systematically review the evidence relating to the support needs of parents and children when a parent is at EOL from cancer.

- to explore the experience for parents as they prepare/prepared for the death of a parent with cancer who has dependent children.

- to explore the perceptions of the needs of parents as they prepare and support their dependent children for the death of a parent from cancer.

- to explore professionals' experiences and perceptions of supporting parents, when a parent of dependent children is at EOL from cancer, until the end of the immediate bereavement period.

- to explore the perceptions of how parents can be best supported in relation to the children, when a parent of dependent children is at EOL from cancer.

1.4 Defining key concepts

End of life (EOL)

'EOL' is when a patient is not on a curative pathway from their cancer and are expected to die within the next twelve months. This includes patients whose death is imminent (expected within hours, days or weeks) and those with advanced, progressive, terminal and incurable cancer (National Palliative and End of Life Care Partnership, 2018).

Actively dying

The term 'actively dying' is when the death of a patient is expected within days or hours (Hui et al., 2014).

Immediate bereavement period

For the purpose of this study, the term 'immediate bereavement period' is from the moment an individual has died until the funeral has taken place.

Dependent children (often referred to as children throughout)

A 'dependent child' is any person aged between 0-15 in a household (whether or not in a family), or aged 16-18 in full-time education and living with his or her parents (Office for National Statistics, 2011).

Young children

A ‘young child’ is one which is primary school aged, between 4-11 years old (Venn et al., 2000).

Teenage children / adolescents

A ‘teenage child’ or ‘adolescent’ is one which is secondary school aged, between 12-18 years old (Venn et al., 2000).

Well-parent / bereaved-parent

The term ‘well-parent’ is used to described the co-parent/partner of the parent who is at EOL from cancer. Following the death of the parent from cancer, the ‘well-parent’ becomes the ‘bereaved parent’.

Ill-parent / deceased parent

The term ‘ill-parent’ refers to the parent who is at EOL from cancer. Following the death that parent becomes the ‘deceased parent’.

Health and social care professionals (HSCPs)

A HSCP is any professional that provides support to a patient and their loved ones surrounding a patient’s condition. Health professionals include doctors, nurses and allied health professionals. Social care professionals include social workers and voluntary organisation coordinators (Macmillan, 2018). For the purpose of this study, focus will be centered on HSCPs involved in the complexity of EOL care, to include oncology and palliative care professionals.

Family-centred care

The impact of cancer affects not only the ill-parent, but the broader micro and meso systems systems within the ill-parent’s life, to include the children (Piha et al., 2005). For the purpose of this study, family-centred care includes parents and their dependent children. Family-centred

care assesses, evaluates and provides psychological care to parents concerning issues related to parenting when living and dying from cancer (Franklin et al., 2019; O'Neill et al., 2018).

Funeral director

A 'funeral director' provides a service to individuals surrounding the organisation and delivery of a funeral of a loved one (Howarth, 2016).

Resilience

'Resilience' is the capacity and process of positive adaptation despite adversity (Luthar, 2006; Russo et al., 2012; Rutter et al., 2015). Resilience as a capacity is an individual's ability to adapt to change, whereas resilience as a process is the ability to recover from challenging situations with the support of protective factors (Masten & Barnes, 2018). Protective factors (often referred to as coping) can help an individual navigate an adverse stressor, whereas risk factors are obstacles to healthy coping (Murray, 2003).

1.5 Thesis structure

This study is presented using thesis with papers format. The thesis is presented in five chapters as outlined in Table 1:

Table 1: Structure of thesis

Chapter	Chapter content
Chapter one: Introduction	This chapter provides an overview of the study context and rationale, the study's aims and objectives and definitions of the key concepts used throughout the thesis. An overview of the thesis structure is provided at the end of the chapter.
Chapter two: Literature review	This chapter begins with a brief overview of the background literature surrounding the needs of parents and children throughout the EOL experience. A summary of the literature surrounding the role and challenges of HSCPs in facilitating support to parents concerning the children when a parent is at EOL is then provided. This is followed by the published systematic review **(Paper 1)**, providing a detailed review of the needs of parents and children when a parent is at EOL. Some relevant theories to the study are then discussed. The chapter ends with an outline of research gaps.
Chapter three: Methodology	This chapter outlines how the study was conducted, including the researcher's philosophical assumptions, research design, sample, sampling and recruitment, ethical considerations, data analysis and rigour and trustwothiness.
Chapter four: Results	This chapter reports the findings from the study. The first part of this chapter reports the findings from the parents at EOL included in the study. This is followed by the findings from bereaved parents included in this study and their perceptions of how best parents can be supported when mum or dad is at EOL from cancer. This has been written in paper format **(Paper 2)**. The third part of this chapter reports the findings of the role of HSCPs in facilitating care and support to parents concerning their dependent children when mum or dad is at EOL from cancer. This has been written in paper format **(Paper 3)** and published in *Psycho-Oncology.* The final section reports the findings of the experiences of funeral directors when a parent of dependent children has died in the immediate bereavement period. This has been written in paper format and published in Death Studies **(Paper 4).**
Chapter five: Discussion and conclusion	The first part of this chapter provides an overall discussion of the findings from the four sample groups included in this study. The second part reports the recommendations for practice, policy and education, as well as the study strengths and weaknesses. The study's contributions to knowledge and directions for future research are also identified. The chapter ends with the study's conclusion.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The first part of this chapter provides an overview to the background literature on the challenges and needs of parents and children when a parent is at EOL from cancer. Literature on the role of HSCPs in providing care and support to parents regarding their dependent children during the EOL experience is also presented. Many of the issues at EOL for parents and professionals are briefly outlined as they are detailed in the study's publications. The published systematic review **(Paper 1)** is presented in section 2.3: *"Challenges and support needs of parents and children when a parent is at end of life: A systematic review".* An updated search was conducted in August 2020, and found no new studies relevant to the review since its publication in July 2019. Relevant theories to the study are then discussed. The chapter concludes with a summary of the research gaps and the need for further research.

2.2 Background literature

This section provides an overview of the background literature on the challenges and needs of parents and children when mum or dad is at EOL from cancer. Literature is reported under four headings: (1) challenges faced by parents, when a parent is at end of life from cancer, (2) HSCPs' challenges of providing supportive care to parents concerning their children, when a parent is at end of life from cancer, (3) the needs of children, when a parent is at EOL from cancer, and (4) the effects of the ill-prepared child, for the death of a parent.

Challenges faced by parents, when a parent is at end of life from cancer

Preparing for EOL is challenging for any family (Grbich et al., 2001). However, there are few experiences more emotionally devastating for parents than dying whilst having dependent children (Fearnley, 2012). Parents' desire is to protect their children from pain and upset, and are often uncertain how, what and when to tell their children mum or dad is going to die from cancer (Beale et al., 2004). A number of obstacles appear presenting as barriers for parents to tell their children mum or dad is going to die from cancer (Hanna et al., 2019). These include parental beliefs that young children (ages 4-11) would not understand the severity of the situation (Bugge et

al., 2014); opposing parental beliefs on how best to support the children for the impending death of a parent (MacPherson, 2005); and parents' uncertainty of how to prepare their children for the death of mum or dad (Turner et al., 2007). Literature has suggested parental emotions often affect open communication between the parents and children regarding the ill-parent's declining health. This included finding it too painful and 'just can't go there' (Stephenson et al., 2015) to tell the children mum or dad is going to die (Kennedy & Lloyd-Williams, 2009b; Park et al., 2017; Stephenson et al., 2015).

Some parents have been reported to have a lack of clear understanding surrounding the poor prognosis themselves, and thus do not feel confident concerning if, how and what they should tell the children regarding the situation (Bugge et al., 2009; Hanna et al., 2019). Many parents have been reported to struggle in finding the appropriate language, as they prepared to tell their children mum or dad is going to die (Kennedy & Lloyd-Williams, 2009b; Phillips, 2015; Tillquist et al., 2016). However, it is not clear from the literature what language is helpful for parents, as they prepare to tell their children mum or dad is going to die (Hanna et al., 2019). Alongside this, some parents have been reported as concerned about difficult questions the children may ask; no more than 'are you (or, how are you) going to die?' (Hockley, 2000; Kennedy & Lloyd-Williams, 2009a). There is a need to understand difficult questions posed by children to parents regarding mum or dad's poor prognosis, declining health and impending death, and how parents can be best supported to navigate such challenging questions with their children.

Parents have reported a desire for guidance and advice from HSCPs on how best to tell the children mum or dad is going to die (Bugge et al., 2009; Kennedy & Lloyd-Williams, 2009a; MacPherson & Emeleus, 2007; Melcher et al., 2015; Phillips, 2015). HSCPs are well-placed and have regular contact with the parents, in both the acute and community settings throughout the EOL cancer trajectory, to provide psychological care and support concerning their children (Franklin et al., 2019; Golsäter et al., 2016). A systematic review highlighted there is a discrepancy between parents' need for instrumental guidance from HSCPs and what is provided in practice (Fearnley & Boland, 2017). This included: parents' desire for guidance from HSCPs on how

to talk to the children in relation to the ill-parent's poor prognosis and ongoing treatment (Turner et al., 2007), and how to prepare the children for the medical environment when visiting the parent during periods of hospitalisation (Barnes et al., 2000). A better understanding of the requirements of parents at EOL regarding their children could inform how, when and what supportive care could be provided by HSCPs, to help future parents, as they prepare their children for the death of mum or dad. A detailed account of the challenges and needs of parents at EOL concerning their children are discussed in **Paper 1** (section 2.3).

HSCPs' challenges of providing supportive care to parents concerning their children, when a parent is at end of life from cancer

The structure of clinical services mean HSCPs have regular contact with parents at EOL, affording unique opportunities for HSCPs to provide support to parents as they prepare their children for the death of mum or dad (Karidar et al., 2016). Alongside this, HSCPs are removed from the emotional tension within the family to provide these aspects of care (Collins et al., 2018). It has been suggested when parents are equipped with informational and emotional support from HSCPs in relation to discussing mum or dad's poor prognosis with the children, it is helpful in facilitating conversations between parents and children regarding the reality of the situation, and involving them throughout the EOL experience (Fearnley & Boland, 2017; 2019; Park et al., 2015; Thastum et al., 2008). This in turn can facilitate better coping for the children in adult life (Ellis et al., 2013).

Despite parents' desire for supportive input from HSCPs concerning how best to prepare their children for the impending death of mum or dad, studies suggest this aspect of care is often not provided in practice (Ellis et al., 2017; Fearnley & Boland, 2017; Franklin et al., 2019; Turner et al., 2007). Literature suggests that HSCPs avoid providing supportive care to parents at EOL concerning their children, as they fear that opening up conversations regarding them may cause added stress to mum or dad's situation (Fearnley, 2012; Clipsham et al., 2015; Turner et al., 2007). Also, studies have suggested HSCPs feel they have inadequate training to provide psychosocial care to parents at EOL regarding their children (Dencker et al., 2017; Franklin et

al., 2019; Hicks & Fide, 2003). Although literature reports HSCPs perceive a lack of training to provide supportive care to parents who are dying regarding their children, it is not clear what HSCPs perceive are the needs of this population, as mum or dad's health declines throughout the EOL period, or when psychosocial input is required by parents.

Other reported obstacles in the literature to HSCPs provision of supportive care to parents at EOL include: a lack of time to provide meaningful support to parents at EOL regarding their children (Karidar et al., 2016); a lack of confidence to engage in conversations with parents at EOL regarding their children (Arber & Odelius, 2018); and a lack of professional experience as a HSCP to provide meaningful support to parents at EOL concerning their children (Davis et al., 2003). However, these studies have predominately explored oncology nurses' perceptions of the barriers to providing care and support to parents at EOL regarding the children (Franklin et al., 2019), whereas there is a wide variety of HSCPs involved in the complexity of a patient's care at EOL.

There are no guidelines available surrounding HSCPs role in the provision of supportive care to parents at EOL regarding their children (NICE, 2004). It is unclear from the literature if, how, what and when HSCPs are providing supportive care to parents at EOL concerning their children, or what is considered as good practice when a parent of dependent children is at EOL from cancer. A better understanding of the needs of HSCPs in providing supportive care to parents at EOL regarding their children can help inform training and guidelines, to aid their provision of this aspect of care in practice.

The needs of children, when a parent is at EOL from cancer

When a parent is dying from cancer, children have reported a desire to be informed regarding their mum or dad's poor prognosis (Christ & Christ, 2006; Muñoz-Sartre et al., 2016), with regular updates surrounding the parent's treatment and declining health (Dehlin & Reg, 2009; Kennedy & Lloyd-Williams, 2009b). Communication between parents and children concerning a parent's illness and declining health has been identified as a protective factor in facili-

tating positive coping for children when a parent is dying from cancer (Ellis et al., 2017; Rauch et al., 2002; Rodríguez, 2020; Sheehan et al., 2019; Walsh, 2016). In line with family systems theory (Broderick, 1993), where children have an understanding of a parent's declining health and impending death, this openness can help reduce their sense of loneliness and isolation and promote a sense of belonging to the family (Eklund et al., 2020; Saldinger et al., 2004; Watson et al., 2006).

It has been reported children desire for opportunities of quality time together as a family when mum or dad is dying from cancer, to promote attachment towards their parents during the stressful EOL experience (MacPherson & Emeleus, 2007) and provide memories for the future for after their parent has died (Alvariza et al., 2017; Bugge et al., 2008). Memory making has been suggested as a protective factor for children as it helps them maintain a connection after the parent has died; often referred to as 'continuing bonds' (Fearnley, 2015; Klass et al., 1996). However, it is unclear from the literature what 'memory making' looks like for families (Hanna et al., 2019). Also, many children desire to be with the ill-parent when they are actively dying (MacPherson & Emeleus, 2007; Tillquist et al., 2017). This has been suggested as a protective factor, as it aids the child's understanding of how the parent died and feeling they were part of the 'saying goodbye' (Holland, 2004). However, it is not clear from the literature if children are present when the ill-parent is dying, or how parents prepare them for this experience (Hanna et al., 2019), which is likely to be new for many of them.

As well as spending quality time with their dying parent, children have reported a desire for normality when a parent is dying from cancer, such as going to school or attending their usual clubs and societies (Dehlin & Reg, 2009; MacPherson & Emeleus, 2007). Maintaining routines, as best as possible, when a parent is at EOL has been identified as a protective factor in providing children with a sense of security and stability (Bugge et al., 2008; Dehlin & Reg, 2009). However, routines can be difficult to maintain as a result of mum or dad's declining health and increased parenting demands placed on the family (Hanna et al., 2019). There is a need to better understand how parents navigate parenting responsibilities and family life when a parent is at

EOL from cancer. The needs of children when a parent is at EOL are discussed in **Paper 1** (section 2.3).

The effects of the ill-prepared child, for the death of a parent

Studies have reported that when information surrounding a parent's poor prognosis and impending death are withheld from young children, the lack of information and inclusion can create fear and worry in them; often feeling they are at fault or the cause of the parent's declining health (Barnes et al., 2000; Beale et al., 2004; Christ et al., 1993; Fearnley & Boland, 2017; Thastum et al., 2008; Visser et al., 2004). Bugge et al. (2008) and Muriel (2017) reported that although the children in their studies were not directly informed about the parent's declining health, the children were reported to have an awareness 'something was different' in the family. It was suggested that the lack of information surrounding the reality of the situation left the children feeling unable to talk to the parents about their insecurities, fears or anxieties (Bugge et al., 2008; Muriel, 2017).

Literature reports that children less prepared for the death of a parent are more susceptive to negative coping and adjustment into adulthood, compared to children who are prepared for the death of a parent. This includes higher levels of anxiety (Rosenheim & Reicher, 1985; Visser et al., 2004; 2005), isolation (Goldman, 2013), guilt (Berg et al., 2016; Gray et al., 2011), anger (Goldman, 2013), difficulties in forming and maintaining trusting relationships (Ellis et al., 2013; Forrest et al., 2006; Muriel, 2017) and behavioural issues (Ellis et al., 2017; Visser et al., 2007). There is a need for parents to be encouraged, equipped and supported to foster an environment of open and honest communication and involve their children throughout the EOL experience, to help facilitate better adjustment into their child's adulthood.

The challenges and needs of parents and children when mum or dad is at EOL from cancer are thoroughly discussed in the published systematic review, which is presented in the next section.

2.3 Published systematic review (Paper 1)

This review synthesised the evidence on the experiences of parents and children when a parent is at EOL. A systematic search of four electronic databases and grey literature searching resulted in the inclusion of 27 qualitative papers to the review. Using Thomas and Harden's (2008) thematic analysis framework for systematic reviews, eight sub-themes were identified, further categorised into two broad themes: (1) barriers and facilitators in sharing the news that a parent is dying, and (2) strategies to manage the changing situation. Findings highlighted parents perceived lack of emotional strength, lack of understanding surrounding the poor prognosis, and emotional tensions between parents were barriers in the provision of telling the children that mum or dad was going to die from cancer. Although challenging to achieve, maintaining normality, maximising social networks, and quality time together as a family were identified as coping mechanisms for parents and children when a parent was dying from cancer.

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Challenges and support needs of parents and children when a parent is at end of life: A systematic review

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Abstract

Background: Preparing children for the death of a parent is challenging. Parents are often uncertain if and how to communicate and support their children. Many parents feel it is protecting their children by not telling them about the prognosis. Children less prepared for parental death from a terminal illness are more susceptive to later adversities. To facilitate coping and moderate for such adversities, there is a need to gain insight and understand the experience and challenges confronted by families.

Aim: This review synthesised evidence on the experiences of parents and children when a parent is at end of life to discern their challenges, support needs and factors that facilitated good practice.

Design: Mixed-methods systematic review.

Data sources: Four electronic databases (CINAHL, PubMed, PsycINFO and Ovid MEDLINE) using MeSH terms and word searches in October 2018. Studies were not limited by year of publication, language or country. Grey literature searches were also completed on Google Scholar and OpenGrey.

Results: In all, 7829 records were identified; 27 qualitative and 0 quantitative studies met the inclusion criteria. Eight descriptive themes were identified, further categorised into two broad themes: (1) barriers and facilitators in sharing the news that a parent is dying and (2) strategies to manage the changing situation.

Conclusion: Lack of understanding in relation to the parent's prognosis, denial and feeling ill-equipped were suggested as barriers for parents to share the news with their children. Engagement with social networks, including extended family relatives and peers, and maintaining routines such as attending school were suggested supportive by parents and children. Findings are limited primarily to White, middle-class two-parent families. A number of areas for future research are identified.

Keywords

Family, children, parents, cancer, advanced cancer, end of life

What is already known about the topic?

- Preparing for end of life of a parent is a stressful period for the whole family. It appears that parents feel not preparing their children for the death of a parent is protecting them.
- Children prepared for the death of a parent have shown better adjustment and require less input in adulthood with psychiatry, compared to children not prepared for the death of a parent.

What this paper adds?

- Parents' perceived lack of emotional strength and unclear understanding of prognosis, children's cognitive developmental stages, as well as tensions between parents, denial and feeling ill-equipped were identified barriers in their provision of sharing the news with their children that their parent was at end of life and dying.
- Although challenging to achieve, maintaining normality and routine, maximising social networks, quality contact and open communication with the end of life and dying parent were identified as supportive coping mechanisms for parents and children when a parent is at end of life.

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Implications for practice, theory or policy

- Findings suggest healthcare professionals need to provide parents with clearer indications where and when possible of a declining situation when prognosis is poor and death is imminent, so they can prepare their children for the impending death of their parent.
- Additional research to identify the challenges and support needs of parents and children of more heterogenous samples of families is needed. In particular, those families who do not avail of support groups and services.

Introduction

There are few experiences more difficult and emotionally devastating for parents than dying while they still have dependent children. While talking about death and dying still remains a taboo in Western society, in 2015, it was estimated that 23,600 parents died in the United Kingdom, leaving an estimated 41,000 child dependents.[1] The authors of this review operationalise 'end of life' as when a patient is not on a curative pathway for their illness and are likely to die within the next year. This includes patients whose death is imminent (expected within hours, days or weeks) and those with advanced, progressive, terminal and incurable conditions.[2] End of life for a parent of dependent children is highly stressful.[3] It is also very challenging for the children and research has reported that they are at greater risk of adverse psychological reactions, including increased levels of aggression, despair and social isolation, anxiety, depression and post-traumatic stress disorder (PTSD), than the general population.[4,5] However, when parental death is expected, parental support is an important protective factor in preventing such psychosocial adversities in children.[6]

While many parents are often uncertain if, and how, to communicate with their children when a parent is dying, evidence highlights that children wish to be informed about their parent's illness and prognosis.[7] As a result of being informed, studies demonstrate that children feel less guilty and feel valued, with reduced isolation.[8] A recent study highlighted that when children have an understanding of the dying process and are prepared for the loss, they show quicker adjustment, than those children who are not informed.[9] Conversely, longitudinal and follow-up bereavement research studies have correlated and reported children unsupported when a parent is at end of life are more susceptive to adversities in their bereavement and later life, including a decline in education, with increased levels of substance abuse, mental health issues and criminality.[10,11] The benefits of open communication between parents and children at end of life are clear, in that it maintains and sustains the parent–child relationship and mediates for such adversities.[12,13]

Despite the overriding need and benefit of open communication, many parents appear not to prepare their children for the death of an ill parent, as they feel not preparing is a method of protecting their children from emotional distress. In addition, parents feel they do not have the language, knowledge, confidence or emotional strength to do so.[14–17] They fear their children will not cope with the information and it will cause them harm, while also being concerned about how they will handle their difficult questions. Other aspects which can add to the complexities encountered while parenting at end of life, with dependent children, include differing developmental stage of the children (especially families with adolescents)[18]; efforts expended by families to create memories[19]; need to mobilise support to meet the practical, emotional and financial needs of the children[20]; and fractured and broken families through divorce and separation.[21]

Most parents desire knowledge and guidance, as well as emotional, practical and social support, so they can positively and assuredly protect and prepare their children for the death of their parent.[20,22] This systematic review aims to synthesise the evidence on the experiences of parents and children when a parent of dependent children is at end of life. Specifically, this review will identify from the experience of parents and children their (1) challenges, (2) support needs and (3) factors that facilitated good practice when a parent of dependent children is at end of life. As a result, the provision of this knowledge will contribute towards the development of supportive interventions, to promote adjustment for future families, as they prepare children for the death of a parent.

Methods

This systematic review followed an a priori protocol according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocols (PRISMA-P) 2015 guidelines,[23] which is a widely recognised standardised guide which facilitated the development and reporting of this systematic review. The review protocol was registered on PROSPERO before the search was completed (registration no. CRD42018087554).

Search strategy

Existing literature was systematically searched to identify articles relating to the experiences of parents and children, when a parent with dependent children (<18 years old) is

Table 1. Search terms used in MEDLINE.

Database: MEDLINE <1946–October, week 3, 2018>	
Search category 1: 'End of life'	**Search category 2: 'Family'**
1. exp Palliative Care/	7. exp Family/
2. life?limiting.mp	8. exp Parent-Child Relations/
3. terminal*.mp	9. parent*.mp
4. palliative.mp	10. mother*.mp
5. end?of?life.mp	11. father*.mp
6. dying.mp	12. child*.mp
	13. adolescen*.mp
Search category 3: 'Challenge, support + good practice'	14. teenage*.mp
15. support* adj3 (emotion* or physical* or spiritual* or psychological* or practical* or social*)	
16. challeng*.mp	**Search strategy**
17. best practice.mp	19. 1 OR 2 OR 3 OR 4 OR 5 OR 6
18. good practice.mp	20: 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14
	21. 15 OR 16 OR 17 OR 18
	THEN
	22. 19 AND 20 AND 21

at end of life. Four electronic databases (CINAHL, PubMed, PsycINFO and Ovid MEDLINE) were searched on October, week 3, 2018, using both Medical Subject Heading (MeSH) terms and text word searches, to increase the search sensitivity. Boolean operator 'OR' and 'AND' were used to combine search terms to broaden or limit the search results, as appropriate. The search terms (Table 1) were generated in consultation with two experienced subject librarians and the first author (J.R.H.). The fully devised search strategy was peer-reviewed using the PRESS tool[24] by two co-authors (E.McC, C.J.S.) (Appendix 1). The search strategy was deployed by the first author (J.R.H.).

Grey literature searches were conducted using Google Scholar and OpenGrey to identify research not indexed in the electronic databases. All authors of relevant papers were contacted via email for any of their updated or unpublished work.

Study inclusion and exclusion

A list of inclusion and exclusion criteria (Table 2) was applied to ensure that only studies relevant to address the review aim were included. This included qualitative and qualitative studies using any research design and analysis that investigated adults (specifically parents) at end of life and have dependent children (less than 18 years old). In addition, studies were only eligible for inclusion if they reported experiences of parents or children when a parent is at end of life. Studies where death was not expected within a 12-month period, known to

Table 2. Inclusion and exclusion criteria.

Inclusion	Exclusion
Study design	
Qualitative research studies using any research design and analysis	Opinion articles
Quantitative research studies using any research design and analysis	
Participants	
Studies investigating adults (specifically parents) who are at end of life and have children under 18 years	Studies where an individual less than 18 years old is at end of life
Studies describing the experience for parents and children, when a parent is at end of life. Only from the experiences of parents and children will challenges, support needs and factors that facilitated good practice be extracted	Illnesses where the parent is not expected to die from the illness. Studies where death is not imminent or known to the participant
Interventions	
Research examining interventions for providing support for families at end of life. Examples of interventions will include all interventions aimed at health and social care workers, organisations and/or families	
Location, language + year of publication	
No restrictions	

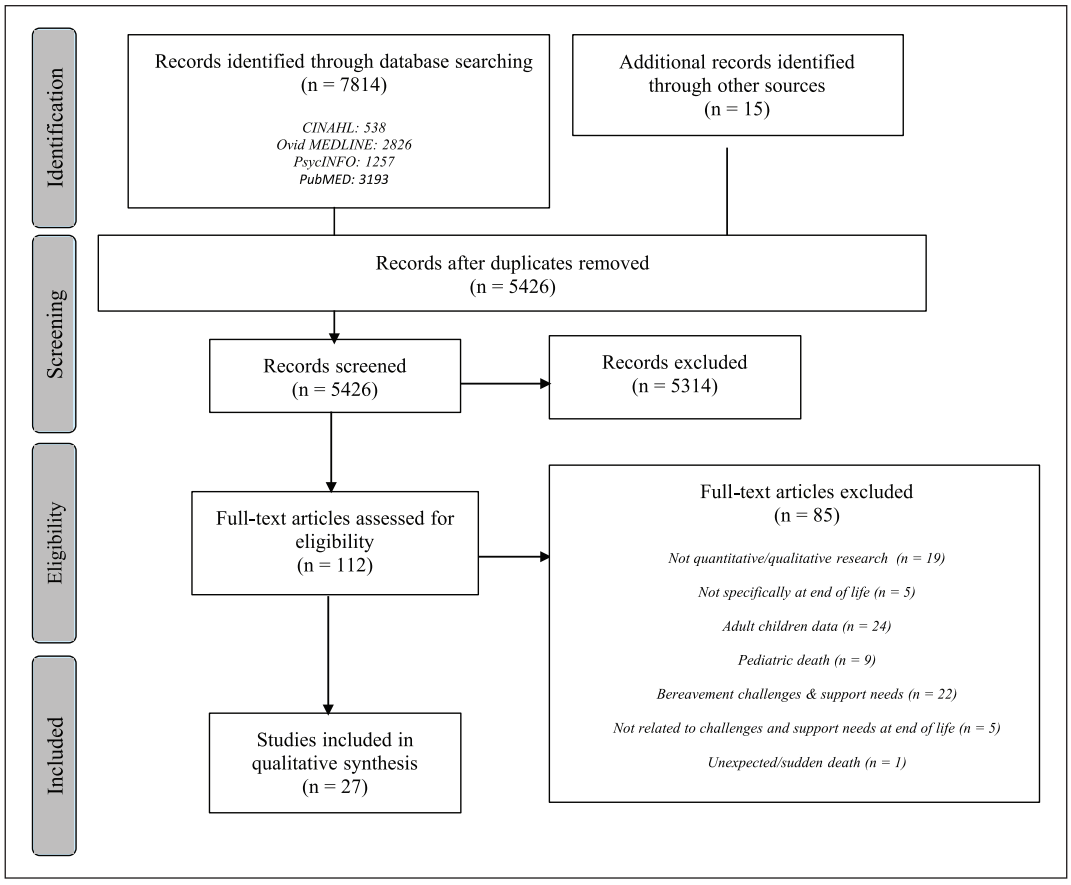

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).

the participant or reported, were excluded. No restrictions were applied to the location of research, language or year of publication to have a comprehensive understanding of the existing literature.

Screening

The searches identified 7829 publications of which 2403 duplicates were removed. The remaining 5426 publications were reviewed by title and abstract, by the first author (J.R.H.). In all, 5314 records were excluded during this process. Full-text papers were retrieved for the remaining 112 articles deemed eligible on the basis of title and abstract. The first author (J.R.H.) identified 27 qualitative articles relevant, when the full text was assessed. These were confirmed by two co-authors (E.McC, C.J.S.). A PRISMA-P diagram illustrates these findings and explanations for excluded articles at the full-text stage (Figure 1).

Data extraction and assessment of included studies

The first author (J.R.H.) independently extracted data using an extraction sheet in Microsoft Excel (2016). Data were extracted on the author(s), year, country, study aim, research design, sample characteristics, key findings and methodological criticisms. The 27 papers were further reviewed by two co-researchers (E.McC, C.J.S.). Any differences in opinion regarding extraction were resolved via discussion. The first author (J.R.H.) applied the CASP quality assessment tool[25] for the 27 qualitative studies, which was verified by two co-authors (E.McC, C.J.S.) (Appendix 2). The CERQual approach was TABlied to assess the methodological limitations, coherence, relevance and adequacy of the review findings.[26] Subthemes received either a low or moderate confidence rating. Full details can be found in Appendix 3.

Data synthesis

As the 27 eligible studies were qualitative, a thematic synthesis was conducted based on the approach by Thomas and Harden.[27] This involved three steps: (1) coding of text, (2) developing descriptive themes and (3) generating analytical themes. The first author (J.R.H.) coded the findings from the extraction form, line-by-line using NVivo v.11. Through discussion, all authors collectively grouped together similar codes and agreed on descriptive themes

that merged together. Together, the authors identified two analytical themes.

Results

Overview

The 27 qualitative studies were published between 2000 and 2018.[5,8,9,13,18–21,28–46] Eighteen of the included studies were conducted before the ill parent died and participants included the ill parent, the healthy parent and/or the children. Nine studies were conducted in the bereavement period and included either the bereaved parent and/or the children. All studies reported parental deaths from cancer. The majority of families were recruited via support groups or services, to which many studies suggested the families included were functioning well as a result of attending. Consequently, findings are limited and represent the subset of the population who attend these groups and services. Furthermore, the majority of participants were from two-parent families, well-educated, White and middle-class living in Western populations. Despite not the norm in clinical practice, many families had frequent access to key support workers and coordinators. As a result, it is unclear how the presented findings are transparent to this population as a whole. Full characteristics of the included studies are presented in Table 3. Eight descriptive themes emerged from the included studies, further categorised into two broad themes: (1) barriers and facilitators in sharing the news that a parent is dying and (2) strategies to manage the changing situation.

Barriers and facilitators in sharing the news that a parent is dying

All the studies in this review suggest parents have a keen desire to protect their children from any further distress when their parent is dying from cancer. Protecting their children was described by parents as choosing whether or not to prepare their children for the death of a parent. Identified barriers and facilitators in preparing children for the death of a parent are discussed under the following subthemes: (1) necessity for information about their illness, (2) guidance and help desired and required to share the news, (3) emotions affecting open communication and (4) parental conflict and informing the children.

Necessity for information about their illness. Of the 27 studies included, a prominent theme across 16 studies was the need to receive information across the illness trajectory. Consequently, where parents did not have clear information or understanding regarding their illness, they reported being ill-equipped to discuss with and prepare their children for the death of their parent. For these parents, they did not feel confident to explain the complexities of their illness and found their children's associated questions particularly difficult.[20,21,30,33–35,37,40,41,45,46] Some bereaved parents felt health professionals avoided providing honest and clear communication to preserve hope and positivity.[40] To prepare their children, ill and healthy parents reported their need to receive detailed and consistent information from health professionals in relation to the prognosis treatments they would receive, how the disease would progress and health decline, and what death would look like, with associated signs to provide a comprehensive understanding of their illness and impending death.[5,19–21,28,33,35–37,40,41,42,45]

Guidance and help desired and required to share the news. Many parents had a desire for guidance and support with the words and language as how to best communicate with their children, surrounding the impending death of the parent. More specifically, how to prepare them for the physical effect of cancer and the side effects of treatment associated with the parent's actual death.[18,21,28,33–35,37,39,41,42,46] It was highlighted by parents that this guidance needed to be tailored to the developmental[20,21,28,34–37] and cognitive[34,35] understanding of their children.

Parents suggested it supportive when they had an understanding as to how their children may respond and react emotionally and behaviourally to losing a parent to cancer.[21,28–30,34,36] Although only reported in one study, some parents suggested it helpful when they engaged in role-play exercises; an opportunity which provided feedback on how to respond to particular questions that may be posed by children.[21] Also, being provided with leaflets, websites and children's literature aided both parents' and children's understanding.[20,30,35] Obtaining guidance and support promoted parents self-reassurance that they were providing their children with age-appropriate information.[21,28,36,38]

It was suggested that some families may not have the capacity to openly prepare their children for the death of their parent[28,36,38] or may require professional input in fractured families.[21] As a result, some parents had a desire, while a minority expressed a need for a health professional to be present when these difficult conversations with their children were taking place.[21,28,35] Despite this, these studies did not explore how a health professional facilitated these complexities.

Emotions affecting open communication. Parents reported avoiding conversations regarding the parent's illness as their method of protecting their children, from the emotional impact, of the inevitable death of that parent.[18,35,42,45] As a consequence of parents' denial of the terminal nature of the cancer, parents suggested they 'just can't go there'.[45] Often, these parents where in denial that death was the reality and were maintaining hope and

Table 3. Study characteristics of included studies.

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Alvariza et al.[28] Sweden	To explore bereaved young adults' advice to healthcare professionals on how to support teenagers when losing a parent to cancer	A single open-ended question	474 young adults who lost a parent to cancer between the ages of 13 and 16	Teenagers desired: to be seen and acknowledged during their parent's illness to spend quality time with their ill parent before the death to be prepared not protected and unprepared for routine and to spend time with peers and friends for open and honest communication about their parent's cancer diagnosis, treatment, prognosis and end of life care	Questionnaire may not have provided in-depth understanding of adolescents challenges and needs Lack of reporting on ethical considerations Data were driven from a survey. This may have been taken out of context. Also, not a full exploration of adolescents' experiences Lack of demographic details on participants
Buchwald et al.[29] Denmark	To describe and understand how children handle life when a mother or father is dying	In-depth interviews	7 children (11–17 years old) 4 boys/3 girls who are living with a seriously ill or dying parent	Children: who were not given honest information about the disease and its prognosis were left with feelings of anxiety, loneliness and sadness used a variety of ways to handle the impending death, such as reformulating the situation as something positive, seeking to control it by magical thinking or resorting to statistical calculations	No specific information was provided on the parent's illness and what phase of 'end of life' they were in Unclear how the video diaries were used for analysis Uncertain if the quotes are from videos or interviews Unclear how children were selected for the study
Bugge et al.[30] Norway	To assess a support programme for children + their families when a parent has incurable cancer	In-depth interviews	12 children from 6 different families (6–16 years old) 8 girls/4 boys 5 children had an ill mother 7 children had an ill father	Children desired: for help to understand themselves and to learn how to deal with a range of difficult and confusing feelings, thoughts and reactions support and information from parents for support from health professionals that was age appropriate	Support needs are reported from children who attended a bereavement support programme only It is unclear of the provision of knowledge that aided children's understanding
Bugge et al.[21] Norway	Parents' experiences and perceptions of a family support programme when one of the parents has incurable cancer.	In-depth interviews	13 parents (ill + healthy parent) All nurturing children between 6–16 years	Parents: had concerns about telling their child their parent would die. needed more knowledge and support about how to cope with their children during the parent's terminal illness. found the support programme beneficial in relation to family functioning, communication and openness.	Findings are represented as 'parents'. It does not separate differences between the healthy + ill parent. Only investigated parents attending a bereavement support group. Unclear as to what the programme was providing parents that was suggested to help them.

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Bugge et al.[19] Norway	Parents understanding of their child's expressions of grief	In-depth interviews	8 parents who had lost a spouse/child ***Only the data relating to the death of the spouse were extracted***	Parents: needed help to understand the important elements of coping and competence and how these influence their child's reactions benefitted from support that helped them to re-establish a healthy family life. This was suggested to enable them and their children to create memories without but still honouring the deceased parent	No reporting of ethical approval or considerations Only investigated grief from parents and children attending a bereavement support programme Some findings refer to children who have lost a sibling. These have been excluded from the analysis in the review
Dehlin and Reg[31] Sweden	To describe adolescents' experiences of a parent's serious illness and death	Open-ended interviews	Five 16- to 18-year-olds (2 female/3 male) who lost a parent to cancer. Interviews were conducted between 8 months and 3 years post death of parent	Adolescents: were focused on hope + pushed away thoughts about the illness had feelings of loneliness despite close proximity of friends + family reported increased levels of maturity following the death with greater comprehension and awareness of relationships and existential values desired to talk + spend time with friends and for them to acknowledge their feelings often avoided conversations with both parents regarding the situation	Although the study acknowledged a relatively even split of gender, no consideration was given if there are differences between gender, in their experiences Demographic details of participants are limited Participants were identified via hospital social workers and therefore are likely to have benefitted from this support service
Hansen et al.[32] The United States	To describe adolescents' continued relationships with a deceased parent	Semi-structured interviews	61 participants from 26 families including 30 adolescents, 20 well parents and 11 ill parents. Post-death interviews were conducted with 15 participants	The study identified ways in which adolescents maintain their relationship with their deceased parent, these being themed as inner guide, encounters and mementos For adolescents, inner guide was the enduring voice or messages from the deceased parent. Encounters were described as a warning sign for potential complicated bereavement and mementos were items that reminded the adolescent of the deceased parent	Data were specific to the United States No clear statement provided on ethical issues While data were collected on parents as well as adolescents, this is not acknowledged in the results Lack of demographic reporting on participants Participants were provided with financial benefits. It's possibly their motivation to participate Findings are reflective of a single hospice service

(Continued)

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Hockley[33] The United Kingdom	Identifying factors that enable families to cope with the dying of a loved one	Case studies	Case study 1: 2 parents and a 6-year-old child Case study 2: 2 parents and a 3-year-old child	Health professionals should perform an assessment to have an awareness of the family unit Multidisciplinary teams should work together, including nurses, social workers, doctors and chaplains to ensure the whole family are included at end of life to ensure a positive death experience	Unclear how the data were obtained No methodology or consideration of ethical issues Not rigorous or systematic A lack of specific reporting of the families in the study, including demographics and support needs
Kennedy and Lloyd-Williams[34] The United Kingdom	To explore how children cope and to identify areas where there may be barriers to children accessing support to enable them to cope	Semi-structured interviews	10 ill parents 7 main carers 11 children	Children: feared how life would be after the death of their parent desired to understand the side effects associated with the treatment desired for normality and distraction when their parent was at end of life. This was often achieved by spending time with friends had a desire to talk with someone outside of the family desired to spend time with the ill parent. This was suggested helped in the bereavement period and kids reported reduced feelings of guilt Parents: desired to maintain routine despite the distressing situation often felt they could not prepare their children because of pre-existing behavioural problems felt their children coped well when they openly communicated with them about their illness felt it was important to maximise their social support networks so they could help maintain routine for their children	Does not indicate where at 'end of life' the parent was A lack of demographics of children Families were identified from attending a support service or were approached via health professionals from specialist services. Further unclear of how many came from each service/group Majority of participants were from White backgrounds. For those from non-White backgrounds, it is unclear whether there are any differences in their experiences

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Kennedy and Lloyd-Williams[35] The United Kingdom	To explore children's information needs and where and how or by whom they wanted to gain the information when a parent is diagnosed with advanced cancer	Semi-structured interviews	10 ill parents 7 main carers 11 children	Children: needed age-appropriate information that they could comprehend wanted information from a variety of sources including healthcare professionals, books, leaflets and the Internet wanted honest information so they could prepare for the future feared talking to their parents as they feared upsetting them Parents: were unsure how honest to be with their children and had uncertainty of what was appropriate to share with them found it difficult to answer children's questions surrounding treatment, side effects and impending death	Does not specifically indicate where at 'end of life' the parent is Some findings refer to children who were not aware of their parent's impending death. These findings have been excluded from any analysis in the review No statement given on the analysis methodology Demographics excluded regarding the age and gender of children Families were identified from attending a support service or were approached via health professionals from specialist services
Kennedy et al.[36] The United Kingdom	To report on the views of children, parents and key stakeholders of a new bereavement support service for families where a parent is dying	Case studies	Six families Each family case study consisted of parent(s), child (up to 19 years), healthcare professionals and family support workers. ***Only data of children up to 18 years were extracted***	Children desired: to journey alongside the parent and have clear, honest and age-appropriate information to escape the chaos at home and maintain routine at school for supportive friends, peers and teachers for teachers to be sensitive to their situation pre and post death opportunities to make independent decisions such as being with the parent when they were actively dying	Unclear at what point in the 'end of life' the parent was at The sample were identified from a palliative care service and may not be representative of individuals who do not avail from these services Unclear how many individuals where involved in each case study – between children/parents/healthcare professionals

(Continued)

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Lundquist[37] The United States	To describe how men diagnosed with advanced cancer understand and navigate their role as a father	Semi-structured interviews	11 fathers (8 Caucasian, 1 Latino, 1 African American, 1 African) Some fathers had children between ages 19 and 28	Men: felt their role as a father and their masculinity was challenged and threatened if they engaged in support services and asked for help felt they did not have the language to communicate their situation with their children under 18 years were often clinging to hope they would survive their illness felt it was important to have support from anyone in their life described financial burdens in supporting their family. It was supportive when they were informed of grants they could avail off reported a new found meaning of family following their diagnosis. Their priorities shifted to the family being first	Findings are reflective of men attending a support service in the United States While the sample included Caucasian, Latino, African and African American fathers, the findings did not illustrate differences in these groups The methods state that there are 11 children from the 11 fathers under the age of 18; however, some men described having more than 1 child under 18, as a result, these findings are not completely reflective of fathers with kids under 18. Some men would have been referring to their adult children.
MacPherson[38] The United Kingdom	To gain understanding of difficulties experienced by well parents in telling children that their parent is dying.	Semi-structured interviews	9 parents (healthy and ill) 2 male/7 female Between them, they had 18 children. 8 of the parents were married/1 was separated	Regrets were made when families did not spend enough time together. Often children were not informed or prepared due to competing claims from the two parents. The ill parent often struggled in accepting their own mortality and therefore this was a barrier to preparing the child.	Ethical considerations are unclear and underreported. Underreporting of participant demographics. Participants were recruited from a counselling service, whom the researcher knew. This may have caused bias in data collection and/or analysis.
MacPherson and Emeleus[39] The United Kingdom	To identify the psychosocial needs of children facing the death and subsequent bereavement of a parent.	Semi-structured interviews	Interviews conducted after the parental death, including: 1 teenager 4 children (aged 6–8) 4 children (aged 9–11) 4 children (aged 12–14)	Children desired: for knowledge and understanding of death. to create memories and spend quality time together before the death. for empathy and others understand the severity of their situation.	No statement provided on the methodology of analysis. Families were recruited from a support group they were attending. Unclear how the support group benefitted families.

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Melcher et al.[18] Sweden	To describe how teenagers are emotionally affected by, and how they try to adapt to, everyday life in a family with a dying parent	Semi-structured interviews	10 teenagers (14–19 years old) consisting of 7 males/3 females, all of whom lost a parent to cancer	Teenagers: valued having distractions from the illness such as going to school who were not fully informed of the parent's prognosis, were making guesses and interpretations that were not accurate, in order to understand the seriousness of the illness and alleviate their uncertainty reported being informed helped them be prepared for the changes they may observe in their parent and understand reported having information about the disease, treatments, side effects and other consequences helped cope with the parent's illness	A semi-structured interview may not capture the richness of the adolescents' experiences' when a parent was dying from cancer Demographic details of participants are limited
Park et al.[40] The United States	To explore experiences of prognostic communication with physicians from bereaved fathers	Open-ended questions using an online survey	244 married men whose wife died within the last 12 months	Bereaved fathers: felt health professionals avoided conversations surrounding end of life as a means to promote optimism and hope in the family had a need for honest and clear information from practitioners wished they had clear information at an earlier stage about their wife's illness so they could prepare for her death and engaged in appropriate services, such as hospice care	Findings are reflective of married men only. Data were excluded on partners. It's likely they have different support needs than those couples married Limited demographic details on participants The online survey may not have captured the full experiences of these bereaved men
Park et al.[41] The United States	To describe the experience of being a parent while living with advanced cancer	Semi-structured interviews	42 parents with advanced cancer who had at least 1 child $<$18 years old	Parents: struggled to adapt to the incurable illness and the impact it had on their children needed to be encouraged to accept their mortality and to prepare their children for loss and make memories while they could reported feelings of anger that they'd miss out on children's development and milestone achievement	Semi-structured interviews may not have captured the in-depth richness of the parenting experiences while living with advanced cancer No statement or consideration given to ethical issues Issues may not be fully explored due to the nature of telephone interviews + challenges in creating rapport Participants were identified and selected based on interviewer self-selection and did not encapsulate the needs of the entire population

(Continued)

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Patterson and Rangganadhan[5] Australia	To examine the needs of parentally bereaved young people	Open-ended questionnaire	34 participants (aged 12–17) and 28 participants (aged 18–23) 81% were under the age 17 or less when the parent died 62% had been bereaved for less than 2 years	Adolescents had a need: for support and understanding for help to cope with their feelings to talk with others who have had similar experiences to have emotional release from the distressing situation to have time to grieve	Participants were recruited from a support group Open-ended questionnaires may not fully capture the challenges and needs of this population Lack of systematic approach to data collection and analysis
Phillips[42] The United States	To gain understanding of the experiences of adolescents when a parent has advanced cancer	Semi-structured interviews	10 adolescents (7 male/3 female) Aged between 3 and 16 All parents had cancer for >5 years	Adolescents: experienced high levels of stress and anxiety when confronted with their parent's terminal cancer needed distraction from the intense situation desired for communication about cancer and social support from peers	No acknowledgement given to the consideration of ethical issues No information provided on the recruitment of the participants in the study A lack of demographic details on the sample
Phillips and Lewis[43] The United States	To provide the adolescent's perspective on the impact of their parent's advanced cancer on their lives	Semi-structured interviews	7 (5 female/2 male) adolescents from six families Between 11 and 15 years old	Adolescents: worked to contain the impact of their parent's illness in their everyday life, self-care, daily routines and in their relationships with their peers worried about their parents and their own future without their parent attempted to protect the ill parent at an emotional cost to themselves found talking about cancer to be helpful but found it difficult to initiative conversations with their parents about the situation	Findings are limited to well-educated, middle-class sample of married couples and adolescent children No statement provided on how ethical considerations were managed Semi-structured interviews may not capture the richness of adolescent's experience when a parent has advanced cancer

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Sheehan et al.[44] The United States	To identify strategies to prepare children for their lives after the parent's death	Semi-structured interviews	26 participants (9 parents, 7 spouses/ significant others and 10 adolescent children aged 12–18)	Participants described varied and creative ways to spend more time together, extend their time together and in some cases, give up their time together Adolescents handled conflict by seeking greater intimacy with their parents and doing tangible tasks for them, but also by retreating to their lives with their friends and doing 'normal activities' when necessary Some mothers perceived themselves as failures because they might not see their children and grandchildren grow up	All participants were recruited from a single hospice and the study suggests they were part of a support programme Findings are reflective of a Western population There is a lack of quotes taken directly from the transcripts into the findings
Sheehan et al.[8] The United States	To explore the complex and dynamic ways in which disclosure occurs when a parent is in hospice	In-depth interviews	22 families where a parent is dying and have adolescent children	Families: that functioned well engaged in measured telling. This was considered the 'model' for a healthy way of telling. This was achieved when parents came to terms with their illness and death before telling the kids that were child-centred engaged in skirting telling. This was talking about death in general terms but not applied to the parent specifically. As a result, adolescents avoided the reality of the situation that were troubled engaged in inconsistent telling. Engagement in this approach resulted in negative consequences such as intense anger in adolescents and inadvertent telling by others outside the family	No statement provided on ethical considerations Unclear statement regarding who the participants were Participants were recruited from a single hospice No statement has been provided regarding the support they may have been providing to parents and/or adolescents
Sheehan et al.[9] The United States	Exploration of the coping strategies by adolescents to manage stressors when a parent is at end of life	Open-ended interviews	22 families pre death 9 adolescents post death	Adolescents cope with the life-limiting illness of a parent by integrating the illness experience into their everyday lives using the distraction of normal activities to avoid worry and maintaining normality as long as possible	Minimal information provided on ethical considerations Families were recruited from a hospice programme and were suggested to be availing of supportive services

(Continued)

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Stephenson et al.[45] The United States	To examine uncertainty as a salient theme for families in which a parent was dying while receiving hospice care	Open-ended interviews	61 participants from 26 families including 30 adolescents, 20 well parents and 11 ill parents Post-death interviews were conducted with 15 participants (including 1 adolescent and 6 adults of the families in time 1 to demonstrate longitudinal findings)	Parents and children: had a desire for more accurate and consistent information as to when the death would happen reported long-term fears after the parent would die including who would look after the children Parents: were unable to answer their children's questions were not communicating and cooperating together and the healthy parent reported feelings of isolation felt it was protecting them by not informing them used the Internet as a source for information when not provided by health professionals	This research is limited to Christian families living in the United States All participants were identified from a single hospice
Tillquist et al.[46] Sweden	To describe female teenagers' experience of losing a parent to cancer	Narrative analysis on blog posts	Five blog posts of females aged between 13 and 19 years old who lost a parent to cancer	Teenagers: experienced a range of emotions during the death of the parent, including anger, sadness, fear and comfort. These were managed by being informed of the illness and journeying alongside the parent; spending time with the ill parent but also escaping the family and spending time with peers and friends who did not journey alongside the parent reported increased feelings of loneliness and anxiety needed awareness of the hospital environment. The hospital was described as a frightening place for teenagers when not prepared	Challenges and support needs are only applicable to female: No acknowledgement as to how these may compare across gender Data were obtained from blogs and therefore can be criticised for lacking systematic research The blog posts may not fully capture the essence of needs by adolescents when a parent is at end of life No statement or acknowledgement was provided as to how informed consent was obtained from the users of the blogs

Table 3. (Continued)

Author(s) Country	Study aim(s)	Research design	Sample characteristics	Key findings	Methodological criticisms
Turner[13] The United Kingdom	To report on young people's experiences of family interactions when a parent is dying	Semi-structured interviews	Post-death interviews were conducted with 15 participants (including 1 adolescent and 6 adult 6 of the families in time 1 to demonstrate longitudinal findings)	Young people: valued openness and honesty reinforcing a sense of closeness and belonging in the face of losing their parent to cancer may have chosen not to ask questions or avoided conversations about aspects of the parental illness, as they preferred not to know preferred to exercise control over their knowledge of the parental illness and prognosis: having the choice over the amount of information they desired to receive preferred not to talk with their parents and relied on friends	Findings are representative of middle-class, well-educated individuals No statement provided on how ethical issues were managed No information provided on the gender of the participants Participants were recruited from a support service in the United Kingdom
Turner et al.[20] Australia	To develop a resource for parents with advanced cancer to empower them in initiating conversation about cancer with their children	Telephone interviews	8 women with advanced cancer aged between 39 and 57. All women had children between ages 2 and 13 at the time of the advanced cancer diagnosis	Women felt: it was important to tell their children about their cancer and to maintain hope in doing so it was supportive when the school were informed as it meant the children could avail of support services it was important to maintain routine and structure for their children they had minimal assistance from healthcare professionals in discussing their diagnosis with their children	Conducting the interviews on telephone may have been a physical barrier to disclosure No statement regarding the methodology of analysis All women were recruited through a support group

optimism that treatment may prolong life.[18,20,37–39,41] As a result, they did not feel the need to directly prepare their children for an uncertain future[20] and often misjudged what their children could comprehend and understand, regarding the severity of the situation.[8,19]

Where open communication was lacking in families, children felt they had a lack of opportunity to admit how they were feeling. Often reluctant to voice their emotional, practical and mental concerns, children feared causing further upset or anger to their parents.[5,13,18,30,34–36,42,43] It was suggested by one author that when open communication was lacking, adolescents became more aggressive with friends and peers,[5] whereas others reported on experienced feelings of loneliness, anxiety and depression[18] and sought information from alternative sources, such as generic and non-specific information from the Internet.[35,45]

On reflection, some parents reported it as their 'moral obligation'[13] to openly discuss and prepare their children for the death of their parent. Parents suggested this open communication provided opportunities to create memories together as a family before the death,[39] maintained and strengthened trusting parent–child relationships,[8,20,37] to share emotions and insecurities,[33] to exercise the family's religious beliefs[8] and provided the children the permission to make their own independent choices, such as being with the parent when they were actually dying.[19,35]

Parental conflict and informing the children. The literature suggested that parents often had competing opinions on how to best support and protect their children.[38] Specifically, in relation to what was best to tell them, the amount of information that should be shared and the timing of this.[21,36,38,39] Some studies suggested conflict was often a result of the ill parent denying the reality of the situation.[18,38,39] Furthermore, it was suggested parents found it difficult to prepare their children when they themselves had a lack of exposure and experience of death and were unsure of what to expect or how to navigate this experience.[38] It was suggested that in those families where the ill parent was not accepting the reality of their illness, the healthy parent who wanted to prepare their children reported feelings of frustration and isolation[39,45] as well as anger and guilt in knowing they would be 'left with the children'.[38] For these healthy parents, it was suggested they had put their frustrations aside, to respect the wishes of the ill parent, while they could still exercise them.[38] Consequently, as a result of these disagreements, children were less well prepared for the death of their parent, and they reported feelings of exclusion, low self-esteem and resentment following the death.[36,42]

Several broken and fractured families through divorce and separation who were attending the support groups were reported to find it challenging to support their former partner in the interest of their children.[21,36,41] A support group mediator was suggested to bring these families together; however, the studies did not explore what their role was.[26,41]

Strategies to manage the changing situation

During the terminal phase of the parent's illness, while the family are faced with new demands and challenges, the literature highlighted strategies viewed as supportive to families to manage the changing situation. The literature demonstrates these strategies through the following subthemes: (1) tensions surrounding spending time together, (2) protective nature of maintaining routine, (3) maximising supportive networks and (4) children's developmental perspective of cancer and death.

Tensions surrounding spending time together. A recurring theme across many studies was the importance for parents and children to spend quality time together before the death occurred to create memories.[19,21,28,30–33,36,37,39,44] Despite this, it was not always possible, where it was suggested that given the health decline in one parent, with reduced mobility and energy, and the other parent with increased financial, practical and parenting responsibilities, there were few opportunities to collectively spend time as a family.[34,42] The literature suggests that due to these increased demands and pressures, some families experienced more arguments, tension and instability.[42] In addition, where memories were not created, as a result of not accepting that death was inevitable, parents and children regretted not valuing the time they had left together in the bereavement period.[18,39,42,44] Contrary to this, those families that managed to spend quality time together reported on the importance of this for creating and providing tangible memories, which were captured through photos, videos, music and crafts.[19,21,30,33,36,39,41,46] Parents and children valued spending time together as a family, before the death of the parent, as it was suggested to be helpful in adapting to the changes following the death.[21,28,31,44] Specifically, children reported satisfaction in reminiscing on positive memories in the bereavement period.[28,31,32,44] Parents felt this was important, as they feared their younger children would forget their dying parent.[21,39]

While ill parents reported feelings of fear, sadness and guilt that they would miss out on the development of their children and the milestones they would achieve,[41] parents and children expressed their desire to maintain a positive atmosphere within the home, with strong and loving relationships, incorporating increased physical and emotional contact.[21,28,37,39,42] This value was reported important by children as it provided them with increased positive memories and attachments to their

parents, despite the emotional impact of the impending death.[21,28,39,46]

The literature documents the importance for contact between the ill parent and their children, when that parent was actually dying.[31,39,44,46] Some children who were not given the opportunity to have final contact with their dying parent reported feelings of sadness and resentment in their grief.[39,46] While some children chose not to,[39] many reported relief in having the choice to say goodbye to their parent.[28,31,39,44,46] This final goodbye was described as important for creating a final memory for the children and made the event concrete.[31,39,44]

Protective nature of maintaining routine. Parents and children had a strong desire for normality and routine, despite the death of the parent being inevitable.[9,18,21,30,31,34,35,39,44] In spite of this, mundane activities were often interrupted due to the demands of the parent's illness, the changes occurring within the family dynamic and financial pressures.[34,37,42] These interruptions were suggested to be distressing and frustrating for the children.[42]

For children, routine was described as a 'protective zone'[31] where they had opportunities to receive empathetic peer-support in sharing their anxieties[30,31,34,35,39,42,44,46] and to have a sense of relief from the intense and distressing situation at home.[5,31,39] Maintaining routine, such as going to school, provided parents and children with distraction, comfort, security and stability, as well as emotional and physical release.[5,18,20,30,31,34,35,39,42,43] Routine granted children the opportunities to spend time with friends, peers and significant others.[5,18,31,34,39,44] This routine, such as school, was suggested to provide parents with reassurance that their children would have supportive networks and environments available before and after the death to off-load their worries, concerns and fears.[20,21,34,39] These factors were suggested to be supportive in facilitating better adjustment in children's grief pre and post death.[42,44,46]

Maximising supportive networks. The disruptive nature of cancer led to increased financial, practical and physical pressures for both parents.[37,42] While not all parents had opportunities to do so,[37] it was suggested supportive for parents to maximise their supportive networks so they could manage their own healthcare and parental responsibilities.[5,20,34,37,41] Extended family members and friends were suggested supportive by parents to help with practical and mundane tasks, such as providing meals and helping with household chores, as well as the practical care of the children, such as taking them to school or activities.[5,20,34,37,41] In addition, parents found it particularly helpful when they were made aware of financial benefits they were entitled to, given changes that often occurred in the parents' employment status due to the cancer.[37] This included being aware of grants to help pay for household expenses or travelling costs to and from hospital/hospice.[37]

For parents and adolescents, having informal connections with other parents/adolescents at support services, who are experiencing the same as them, was supportive in knowing they were not alone.[5,20,37] For parents specifically, these services were suggested helpful in sharing practical and emotional strategies to help support and prepare their children for the death of their parent.[20,37] This included art therapies.[20]

Some fathers reported discomfort in attending support services and seeking help from family, friends and colleagues.[37] These fathers felt it exposed their emotional vulnerability and challenged societal stereotypes of being a man and the provider of the family. Some of the fathers believed seeking help 'would be a sign of weakness'.[37] These fathers suggested it was their wife who helped them understand and accept the need for help financially, practically and socially.[37]

Children's developmental perspective of cancer and death. In the majority of studies included, most of the children highlighted their need to understand cancer and death. Many studies suggested that children had reduced feelings of loneliness and a sense of belonging when they had an improved understanding of the family situation.[8,18,29–31,34,35,43] The factors highlighted by these studies to facilitate children's understanding of the pending death of their parent included being provided with practical and realistic information regarding how their parent's disease would progress, detail on what death would look like and when it was likely to happen, life after death in relation to where the dying parent would go, as well as family life following the death.[8,13,29–31,34,35,43] This information was centred on the level of their understanding.[5,21,31,39,42,46]

While children of all ages wanted to have an understanding of what their parent's death would look like,[21,29,39] it was suggested that young children (typically ages 4–11) had a need to understand the effects of the cancer and the treatment. When young children had the provision of this knowledge, it was suggested to be helpful in managing their fears and anxieties.[19] Furthermore, young children expressed their need to experience empathy. For these children, it was suggested reading books incorporating characters experiencing similar pain normalised these events for children and created a sense that they were not alone.[39]

As the health of the ill parent was deteriorating, while they were aware of the situation, many adolescents reported difficulty in accepting the death of their parent, where they demonstrated heightened levels of fear, anxiety and resistance.[5,18,28,31,42,45,46] For these adolescents, it was necessary for their parents, teachers and peers to understand that they may have chosen to become withdrawn, so they could process the reality of the situation

alone and prefer not to visit or speak with either parent.[9,31,39,45,46] Some adolescents reported starting the process of accepting and grieving the death of the parent before the event occurred, as part of their own coping. As a result, these parents needed to understand coping mechanisms for dealing with death and grief vary and that adolescents may not respond in the expected way.[31]

Many adolescents reported feelings of isolation, loneliness, frustration and anger when their peers and friends could not express empathy and compassion to their situation.[5,18,31,39,41,42,46] To the contrary, teachers, chaplains and cancer charity volunteers/coordinators were identified as valuable individuals by parents and children in advocating children's peers and friends understand their situation.[5,20,30,39,41,42] In doing so, adolescents were suggested to be more willing to open-up and share their feelings with friends or peers and was helpful in coping with the demands of everyday life.[20,33,41] The literature suggested additional means as to how teachers can be supportive to adolescents. This included being sensitive in their teaching of specific topics, for example, adolescents may find it upsetting to read pre-scripted texts about family members in a foreign language[9,39] and appreciating children's anxieties and pre-grief concerns may affect their concentration, motivation and scholastic performance.[5,42]

Children expressed their need to understand death.[19,31,39] Existentially and practically, children expressed their need to know the process of dying and what would happen to their parent when they would die[19,31,39] and, if applicable to families, the concept of heaven according to their religious beliefs.[19,31] Within the studies, death was only described to children using the concept of heaven. The literature suggests this was constructed as helpful by children, as they viewed it as a place where their parent would not be suffering and see them again.[19,31,39]

Discussion

This review has highlighted published findings on the challenges and support needs of parents and children when a parent is at end of life. However, findings are reflective of middle-class two-parent families who attend support groups and services. Other literature has demonstrated that support groups and services are disproportionately underused by certain groups including men, families from complex and fractured dyads, as well as minority and low socioeconomic status (SES) and educated backgrounds.[47,48] To this end, literature has further illustrated that children from low-SES and educated backgrounds are at greatest risk of internalising problems, including anxiety, depression and PTSD, when a parent is at end of life.[49,50] The current studies have not accounted for the challenges and support needs of these populations. Furthermore, over half of the 42% of couples divorced within the first 10 years of marriage in the United Kingdom are estimated to have at least one child under 16 which contributes to an overall estimate of one-in-four lone-parent families of dependent children in the United Kingdom.[51] In addition, the majority of families fractured through divorce and separation are from low-SES backgrounds.[52] The current studies have not accounted for the profound and complex challenges and support needs of these families, as they navigate the end of life experience. Also, relevant studies included only reported parental deaths from cancer and has not considered the impact of other morbidities, such as AIDS. Proportionately, future research should devise more robust recruitment procedures to incorporate the needs of other morbidities and hard-to-reach families, outside of groups and services and reflect this population and society as a whole.

The identified needs from these studies were largely influenced by both the developmental understanding of children and parents wanting to protect their children. The findings, their relevance to other literature, limitations and unanswered questions are now discussed from the 27 papers under two main themes: (1) protective parenting and preparing children and (2) coping and social support.

Protective parenting and preparing children. While all parents have an innate response to maintain responsibility and protection in the caregiving of their dependent children, parents may exert their protection and not prepare them for the death of a parent. It is possible that parents' denial of the reality of the terminal illness affects their emotional readiness to prepare their children. For children less prepared, they have shown increased levels of hostility, resentment, guilt and anxiety in their grief, compared to their counterparts who are prepared for the death of a parent.[35,39] Longitudinal research has demonstrated the benefits of preparing children in that they are less susceptive to psychiatric problems, including clinical depression, if they are prepared for the death of a parent.[49,53]

It was clear from the studies analysed within this review that spending quality time together, before the death, was an important factor for children in facilitating better adjustment in their grief.[19,21,28,30–34,36,37,39,41,44,46] Other literature suggests it encourages children to share memories they have with that parent, which are suggested helpful to reminiscence on, during difficult days, when they are grieving.[54,55] Furthermore, it was suggested that identifying and maximising networks inside and outside the family reassured parents that their children would have supportive networks pre and post bereavement.[5,20,30,31,33–35,37,42–44,46] These findings have been echoed in studies of aging and dying parents of children with developmental disabilities, where these parents have reported it reassuring and comforting to know people would care and love their children, when they no longer would be able to.[56,57]

Having the choice to be with the parent when they were actually dying was suggested helpful in adjusting to life post bereavement for children.[31,39,44] Supplementary literature further suggests that children have reported the experience less traumatic than anticipated and seeing a dead body was less distressing, than they imagined.[58,59] The studies did not explore pre-bereavement challenges and support needs of these families. For example, how was the impending death explained to the children before the event happened. While many studies suggested parents used the concept 'heaven' to explain where the dead parent had gone,[19,30,31,39] it only serves as a non-biological understanding of death[60] and can be confusing to be understood based on the developmental maturation of young children.[61] As a result, it is important that biological underpinnings are described, so the child fully understands death is a permanent state and they cannot 'visit' this place where their parent is 'happy'. However, the studies in the review did not acknowledge this or provide reference as to how families with non-religious beliefs explained death in the pre-bereavement period to their children.

All of the studies in the review suggested parents found it challenging to know what to share or how to prepare their children for the death of a parent. To this end, other literature highlights children's understanding of cancer and death is underpinned by their cognitive developmental maturation.[62–65] With this, parents were suggested to find it supportive when they were provided with the words and language from the service coordinator/facilitators on how to prepare their children accordingly. Despite this, the studies did not report what these were. In addition, not all families have access to support services, groups or coordinators/facilitators and therefore it is not understood how parents explain these complexities to their children in this absence.

Furthermore, despite children's desire for more information, it is difficult to provide factual information given cancer is associated with an ongoing and changing journey of uncertainty. For example, the desire for a timeline as to when the death would occur, cannot be factually answered, as it's impossible to predict when a death would occur. This is further influenced by variables including if the parent responds to any palliative or alternative treatments. To this end, the studies did not highlight how these questions and concerns were managed within families. However, it is important that health professionals are providing realistic indications when and where possible of poor prognosis, declining health and when death may be imminent.

Coping and social support. The review identified many coping and social support mechanisms suggested to facilitate better adjustment for the family, pre and post the death of the parent. For example, children's desire to have normality and routine was needed to have release and distraction from the intense situation at home.[5,9,18,20,21,30,31,34,35,39,42–44,46] In conjunction with studies when a parent is receiving active treatment, maintaining routine, as best as possible during the illness, has been identified as instrumental in providing children with a sense of belonging and purpose[15,66] and controls for problems in later life, such as alcoholism.[67,68] In addition, in line with Family Systems Theory,[69] attempts to minimise distortions to the family routine, during illness, has been identified as a coping strategy for children to manage their stress and anxiety, associated with parental illness.[70,71]

In addition to maintaining routine, such as going to school, the studies in the review demonstrated that teenagers needed to spend time with friends and peers for emotional release.[5,18,31,39,44] Further to this, other studies suggest the desire to spend more time with friends and peers may be a result of the social behavioural changes that occur in adolescence.[72] Research illustrates that during adolescence, teenagers' relationships with their peers and friends become more intimate[73] that they would rather spend more time with others their own age, to exercise their own dependence and autonomy.[74] Another study suggests teenagers find their friends equally as important as their parents.[75] The authors interpret these findings in that it is important that teenagers have 'permission' to adapt to the changes that occur with adolescence, during the stressful period and teenagers may prefer having conversations with their friends and peers, than their parent(s), about the illness.

Fathers' rejection of accepting support and help as a threat to their masculinity or role of being a father has been echoed in other literature, where they have suggested men attributed to a hegemonic masculinity see it as a weakness to avail of help and support.[76,77] However, this finding was only reported in the one study which included non-Caucasian participants[37] and has been identified in previous literature as a trait in non-Caucasian men.[78] Also, the study did not acknowledge this cultural difference.[37] In addition, this finding cannot be considered as a one size fits all, given different interpretations of masculinity, gender and personality.[79] Furthermore, the suggestion that it was the wife who encouraged these men to accept support and help at end of life may be a result of pre-existing roles of parenting within the family.

Moreover, not all families may have supportive networks such as the extended family members, neighbours or community organisations to help with mundane and practical tasks, or have access to support groups or service facilitators/coordinators.

Young children expressed a greater need for physical contact with their parents within a positive home environment, pre and post the death.[31,42,46] Attachment theory may provide a plausible explanation for this increased contact where young children need a secure adult

caregiver for normal social and emotional development to occur.[80] Furthermore, studies have suggested that when one parent dies, children display increased reliance on the other, which is important for facilitating the grief process and producing new and existing parent–child bonds.[81,82] Despite the importance of attachment, these harmonious scenarios are arguably not representative for the reality of these families, where creating a positive home environment, with increased time sitting together, is amiably a skewed version of reality. Parental cancer and end of life is associated with increased levels of distress and anger for the whole family.[82,83] Future research should report the reality for these families, including the negative effects.

All studies suggest power in open communication and family cohesion, where children were suggested to have reduced feelings of loneliness and anxiety and felt valued, when they were prepared for the death of their parent. Other studies advocate this communication within families as a coping strategy for children when a parent is ill.[84] It has been suggested to reduce children's anxiety by having opportunities to freely talk with their parents about their cancer,[85] reduce mistrust between parents and children,[86] and reduce PTSD symptoms when they can openly talk with the healthy parent, about their ill parent, after the death.[87] Open communication during illness has also been suggested to manage conflict and create a more cohesive parent–child environment[87–89] as well as stronger and dynamic relations among couples.[90,91]

Limitations and directions for future research

All studies were conducted between Australia, the United Kingdom, Scandinavia and the United States. This raises concerns as to how the identified challenges and support needs extend to non-Western populations or ethnic minorities living in Western societies. It is important for future research to consider more heterogeneous samples of families; for example, parenting and child-rearing practices in non-Western cultures may impact the challenges and support needs of parents and children, when a parent is at end of life.

Although all included papers were assessed by the three authors (J.R.H., E.McC, C.J.S.), the initial screening was only conducted by the first author (J.R.H.). While careful consideration was given to this process with papers screened by title and abstract on more than one occasion, it is possible relevant articles may have been missed.

Some of the studies in the review reported positive factors suggested to facilitate better adjustment for families, when a parent is at end of life. Despite this, in the absence of longitudinal follow-up with these families, it is difficult to assess the impact these factors had on the long-term adjustment for these families. In addition to this, the studies did not provide specific details on many factors suggested to be supportive, which future research should explore. For example, (1) the role of teachers, chaplains and charity volunteers; (2) what leaflets, websites, forums and role-plays are helpful; and (3) how do health professionals facilitate conversations in broken and fractured families as well as between parents, who cannot mutually agree on what to share with their children, when a parent is at end of life. Furthermore, it is not typically the norm in clinical practice for children to have access and conversations with health professionals. As a result, it is unclear where children's questions are directed in this absence.

Within the literature, there is an inconsistent use of terminologies. While the current review investigated 'end of life', some researchers may refer to this as 'advanced' or 'terminal'. Although the search strategy deployed was sensitive to this, it is possible that research papers were missed due to different interpretations of these terminologies.

All the studies in this review addressed the support needs of families impacted by parental cancer at end of life, but future research should also represent the needs of parents with life-limiting, non-malignant diseases, who have dependent children. While research studies have investigated parenting with other chronic conditions (such as HIV/AIDS),[92,93] and while patterns and similarities may occur in these papers, they were not included in the current review as they did not match the study inclusion/exclusion criteria. Specifically, they did not make it clear if the parent was at end of life. Papers were only included if they specifically made it clear that parent had the awareness they were going to die, very likely within a 1-year period. Finally, for parents to comprehend and process their illness and situation, there is a need for health professionals to provide parents with factual and accurate information regarding their prognosis.

Conclusion

This review has identified that parents need to openly communicate and prepare their children to facilitate a better adjustment when their parent is at end of life. The findings demonstrate parents' lack of understanding in relation to the parent's prognosis and impending death, denial, feeling ill-equipped, as well as tensions between parents were identified barriers in sharing the news with their children. In addition, this review highlights that parents have a desire and need for a clearer indication from healthcare professionals when the parent's prognosis is poor and death is imminent, so they can prepare their children for the impending death of their parent. The studies highlighted coping mechanisms suggested to be supportive for parents and children when a parent is at end of life. This included supportive friends, peers, neighbours, relatives and community groups such as the school. Despite this, studies often did not report the negative

effects or reality for many families. For example, findings are not generalisable to the entire population, as they are reflective of middle-class two-parent families living in Western societies who attend support groups and services. To best support families when a parent of dependent children is at end of life, future studies should consider more heterogeneous samples of families, such as complex family dyads and individuals from lower educated and SES backgrounds.

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Appendix 1. Peer review of search terms using the PRESS (2015) tool.

Question	Response	Question	Response
Translation of the research questions		Are subheadings attached to subheading headings?	Yes
Does the search strategy match the research question/PICO?	Yes	Are floating subheadings and terms in free text used for each concept?	N/A
Are the search concepts clear?	Yes	**Text word searching**	
Are there too many or too few PICO elements included?	No	Does the search include all spelling variants in free text (e.g. UK vs US spelling)?	Yes
Are the search concepts too narrow or too broad?	Ok	Does the search include all synonyms or antonyms (e.g. opposites)?	Yes
Does the search retrieve too many or too few records?	Ok	Does the search capture relevant truncation (i.e. is truncation at the correct place)?	Yes
Are unconventional or complex strategies explained?	N/A	Is the truncation too broad or too narrow?	Ok
Boolean and proximity operators		Are acronyms or abbreviations used appropriately? Do they capture irrelevant material? Are the full terms also included?	Yes
Are Boolean or proximity operators used correctly?	Yes	Are the keywords specific enough or too broad?	Ok
Is the use of nesting with brackets appropriate and effective and effective for the search?	Yes	Have the appropriate fields been searched?	Yes
If NOT is used, is this likely to result in any unintended exclusions?	N/A	Should any long strings be broken into several shorter search statements?	No
Could precision be improved, by using proximity operators (e.g. adjacent, near, within) or phrase searching instead of AND?	No	**Spelling, syntax, and line numbers**	
Is the width of proximity operators suitable (e.g. might adj5 pick up more variants than adj2)?	Yes	Are there spelling errors?	No
Subject headings		Are there any errors in system syntax?	No
Are the subject heading relevant?	Yes	Are there incorrect line combinations or orphan lined?	No
Are any relevant subject headings missing; for example, previous index terms?	No	**Limits and filters**	
Are subject headings exploded where necessary and vice versa?	Yes	Are all limits and filters used appropriately and relevant given the research question?	Yes
Are major headings ('starring' or restrict to focus) used? If so, is there adequate justification?	N/A	Are all limits and filters used appropriately and relevant for the database?	Yes
Are subheadings missing?	No	Are any potentially helpful limits or filters missing?	No
Are any subject headings too broad or too narrow?	Ok	Are sources cited for the filters used?	N/A

Appendix 2. Critical appraisal of included studies using the CASP tool (2013).

Included studies	Clear statement of aims	Qualitative methodology appropriate	Research design appropriate to address research aim(s)	Data collected appropriately to address research issue	Relationship between researcher and participants adequately considered	Ethical issues taken into consideration	Data analysis sufficiently rigorous	Clear statement of findings	Is the research valuable
Alvariza et al.[28]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Highlights challenges and support needs of teenagers who have experienced the death of a parent.
Buchwald et al.[29]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Provides some knowledge of how children understand death and the changing situation A lot of information not relevant for the current review
Bugge et al.[30]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Provided in-depth knowledge on children's experiences, challenges and support needs when a parent has incurable cancer
Bugge et al.[21]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	In-depth understanding of how parents cope at the end of life. A good understanding of balancing family dynamics
Bugge et al.[19]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Good understanding of how the healthy parent and children cope following the death and their support needs
Dehlin and Reg[31]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	In-depth understanding of the challenges and support needs of adolescents who have lost parent to cancer
Hansen et al.[32]	Yes	Yes	Yes	Yes	Yes	Moderately	Yes	Yes	Highlights how adolescents' remember their parent after they've died and the importance of mementos and memories.
Hockley[33]	Yes	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Relatively	Demonstrates the importance of how a healthcare professional can support a parent who is at end of life in relation to their children. A lack of in-depth reporting in the case studies
Kennedy and Lloyd-Williams[34]	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Demonstrates some of the challenges, support needs and factors that facilitated good practice when a parent is at end of life
Kennedy and Lloyd-Williams[35]	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Highlighted challenges and support needs of parents and children when a parent has advanced cancer
Kennedy et al.[36]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Demonstrates challenges and support needs of children and parents when preparing for the death of one parent
Lundquist[37]	Yes	Yes	Yes	Yes	Yes	Yes	Relatively	Relatively	Highlighted some challenges and support needs of fathers who are at end of life
MacPherson[38]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Highlighted the challenges and support needs of the healthy parent when balancing family dynamics, when the other parent is dying

(Continued)

Appendix 2. (Continued)

Included studies	Clear statement of aims	Qualitative methodology appropriate	Research design appropriate to address research aim(s)	Data collected appropriately to address research issue	Relationship between researcher and participants adequately considered	Ethical issues taken into consideration	Data analysis sufficiently rigorous	Clear statement of findings	Is the research valuable
MacPherson and Emeleus[39]	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Identified challenges and support needs of children when a parent is at the end of life from the child's, parent's and health care professional's perspectives
Melcher et al.[18]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Reports on experiences from teenagers as they prepare for the death of their parent
Park et al.[40]	Yes	Yes	Relatively	Relatively	Yes	Yes	Relatively	Yes	Highlights the need for healthcare professionals to provide honest and clear communication when a parent is at end of life from cancer
Park et al.[41]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	In-depth understanding of how parents manage parenting challenges while living with advanced cancer
Patterson and Rangganadhan[5]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Highlights challenges and support needs from young adults who lost a parent during adolescence to cancer
Phillips[42]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	In-depth understanding of the experience of adolescents when a parent has advanced cancer
Phillips and Lewis[43]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	In-depth understanding of the experience of adolescents when a parent has advanced cancer
Sheehan et al.[44]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Demonstrates the importance of spending time together before the death of the parent
Sheehan et al.[8]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Highlights the different communication approaches deployed by parents and the effectiveness of these as they parents prepare children for the death of their parent
Sheehan et al.[9]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Identifies how adolescents cope pre and post death of their parent
Stephenson et al.[45]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Highlights many of the challenges and unmet needs of parents and children as they prepared for the death of a parent
Tillquist et al.[46]	Yes	Yes	Relatively	Relatively	Yes	Unclear	Unclear	Yes	Provides a natural exploration of female adolescents' experience of losing a parent to cancer
Turner[13]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Highlights young peoples' experiences and challenges when a parent is dying
Turner et al.[20]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Highlights support needs of parents as they prepare their children for the death of their parent

Appendix 3. CERQual.

Subtheme	Studies contributing to this subtheme	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQUAL assessment of confidence	Explanation of judgement
Necessity for information about their illness	All studies excluding Buchwald et al.,[29] Dehlin and Reg,[31] Hansen et al.,[32] MacPherson,[38] MacPherson and Emeleus,[39] Melcher et al.,[18] Phillips and Lewis,[43] Sheehan et al.[8,44] and Turner[13]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (14 studies were moderately relevant; 2 study had partial relevance)	Minor concerns about coherence of data (data reasonably consistent within and across all studies)	Minor concerns about adequacy (13 studies offered moderately rich data; 3 studies had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy
Guidance and help desired and required to share the news	All studies excluding Bugge et al.,[19] Dehlin and Reg,[31] Hansen et al.,[32] Park et al.,[40] Patterson and Rangganadhan,[5] Phillips and Lewis,[43] Sheehan et al.,[8,9,44] Stephenson et al.[45] and Turner[13]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (14 studies were moderately relevant; 2 study had partial relevance)	Minor concerns about coherence of data (data reasonably consistent within and across all studies)	Minor concerns about adequacy (14 studies offered moderately rich data; 2 studies had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy
Emotions effecting open communication	All studies excluding Alvariza et al.,[28] Buchwald et al.,[29] Bugge et al.,[21] Dehlin and Reg,[31] Hansen et al.,[32] Hockley,[33] Park et al.,[40] Sheehan et al.[9,44] and Tillquist et al.[46]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (all studies were moderately relevant)	Minor concerns about coherence of data (data reasonably consistent within and across all studies)	Minor concerns about adequacy (13 studies offered moderately rich data; 4 studies had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy
Parental conflict and informing the children	Bugge et al.,[21] Kennedy et al.,[36] MacPherson,[38] MacPherson and Emeleus,[39] Melcher et al.,[18] Phillips[42] and Stephenson et al.[45]	Minor methodological limitations (all studies had minor methodological limitations)	Moderate concerns about relevance (3 studies were moderately relevant; 4 studies had partial relevance)	Minor concerns about coherence of data (data reasonably consistent within and across the studies)	Substantial concerns about adequacy (1 study offered moderately rich data; 6 studies had partial relevant	**Low confidence**	This theme was graded as low confidence because of moderate and substantial concerns regarding relevant and adequacy, respectively

(Continued)

Appendix 3. (Continued)

Subtheme	Studies contributing to this subtheme	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQUAL assessment of confidence	Explanation of judgement
Tensions surrounding spending time together	All studies excluding Buchwald et al.,[29] Kennedy and Lloyd-Williams,[34,35] MacPherson,[38] Park et al.,[40] Patterson and Rangganadhan,[5] Phillips and Lewis,[43] Sheehan et al.,[8,9] Stephenson et al.,[45] Turner[13] and Turner et al.[20]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (12 studies were moderately relevant; 3 studies had partial relevance	Minor concerns about coherence of data (data reasonably consistent within and across all studies)	Minor concerns about adequacy (11 studies offered moderately rich data; 4 study had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy
Protective nature of maintaining routine	All studies excluding Alvariza et al.,[28] Buchwald et al.,[29] Bugge et al.,[19] Hansen et al.,[32] Hockley,[33] Kennedy et al.,[36] MacPherson,[38] Park et al.,[40] Sheehan et al.,[8] Stephenson et al.[45] and Turner[13]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (15 studies were moderately relevant; 1 study had partial relevance	Minor concerns about coherence of data (data reasonably consistent within and across all studies)	Minor concerns about adequacy (15 studies offered moderately rich data; 1 study had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy
Maximising supportive networks	Kennedy and Lloyd-Williams,[34] Lundquist,[37] Park et al.,[41] Patterson and Rangganadhan,[5] Phillips[42] and Turner et al.[20]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (5 studies were moderately relevant; 1 study had partial relevance	Minor concerns about coherence of data (5 studies were reasonably consistent; within and across all studies; 1 study was inconsistent)	Minor concerns about adequacy (4 studies offered moderately rich data; 2 studies had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy
Children's developmental perspective of cancer and death	All studies excluding Hansen et al.,[32] Kennedy et al.,[36] Lundquist,[37] MacPherson,[38] Park et al.[40] and Sheehan et al.[44]	Minor methodological limitations (all studies had minor methodological limitations)	Minor concerns about relevance (18 studies were moderately relevant; 3 studies had partial relevance	Minor concerns about coherence of data (data reasonably consistent within and across all studies)	Minor concerns about adequacy (17 studies offered moderately rich data; 4 studies had partial relevance)	**Moderate confidence**	This theme was graded as moderate confidence because of minor concerns surrounding methodological criticisms, relevance, coherence and adequacy

2.4 Theoretical background

This section reports the theories that were considered relevant for this study. Theory can help a researcher understand the behaviour of individuals, groups or the phenomena of interest (Parahoo, 2014). Alongside this, theory can provide a researcher with a guide to support their interpretation of the data (Wu & Volker, 2009). Given the volume of theories that could be considered to help understand the phenomena of a parent with dependent children at EOL, it was important to limit discussion to the theories perceived most relevant. First, it was pertinent to consider that EOL is a stressful experience (Emanuel et al., 2004); particularly when the individual who is dying is a parent of dependent children (Fearnley & Boland, 2017). It was perceived appropriate to consider coping theories for this study that can help to understand how parents of dependent children navigate and cope during the distressing dying experience (Lazarus & Folkman, 1984). Also, family resilience theory (Walsh, 2016) was considered relevant as it has a focus on how positive coping and adaption could be promoted within families when a parent of dependent children is at EOL from cancer. Second, consideration was given to theories surrounding death and grief that can help to provide an understanding of the behavioural and cognitive reactions of individuals facing death (Kübler-Ross, 1969). These three theories are now discussed.

Lazarus and Folkman's (1984) Cognitive stress, appraisal and coping theory

Coping has been defined as the cognitive and behavioural efforts aimed at managing a situation (Folkman & Lazarus, 1984; Lazarus & Folkman, 1984). Folkman and Lazarus (1988) suggested that coping is influenced by a person's cognitive appraisal of an event which influences an emotional response. It has been suggested there are two types of coping responses: emotion-focused coping and problem focused coping (Folkman & Lazarus, 1988; 1990; Lazarus & Folkman, 1987). Emotion-focused coping aims to reduce the negative emotional response using techniques such as distraction and wishful thinking. In relation to the EOL experience when a parent is dying from cancer, it may be suggested that parents' denial surrounding the reality of the poor prognosis is an example of emotion-focused coping, as well as parents' hope for a cure being available (Hanna et al., 2019).

Problem-focused coping aims to target the cause of the stress by reducing the stressor (Baker & Berenbaum, 2007). Eight problem-focused coping techniques have been identified, to include taking responsibility, accessing social support, positivity, distancing, problem-solving, avoiding escape, self-control and confronting the stressor (Folkman et al., 1986). Problem-focused coping techniques can be positive or negative depending on the individual's personal or environmental context (Biggs et al., 2017). Accessing social support has been reported as helpful for parents when a mum or dad is dying from cancer, such as meeting other parents who are going through a similar experience, and availing of social networks to help with the practical aspects of parenting at EOL (Lundquist, 2017; Patterson & Rangganadhan, 2010). It may be argued that telling the children the reality of the situation that mum or dad is going to die is also an example of parents 'confronting the stressor'.

Literature has suggested that emotion-focused coping strategies are often less effective than problem-focused techniques, as they do not address the root of the stress (Stanton et al., 2000, 2002). Alongside this, it has been suggested that problem-focused coping rather than emotion-focused coping techniques promotes better psychosocial adjustment for the individual's future after the adverse event (Herman & Tetrick, 2009; Ransom et al., 2005; White et al., 1992). Studies have reported that patients perceived to adopt problem-focused coping techniques surrounding their declining health reported higher scores on a scale of life satisfaction, compared to patients at EOL perceived to deploy emotion-focused strategies regarding their poor prognosis (Ahadzadeh & Sharif, 2018; Garg et al., 2018; Sari et al., 2019). Further qualitative research will help to identify problem-focused coping techniques and how these could be promoted within parents of dependent children, when mum or dad is dying from cancer. Subsequently, this could facilitate better adjustment for the family into bereavement. Similarly, additional qualitative research may identify how problem-focused coping techniques could promote HSCPs' provision of supportive care to parents at EOL concerning their children.

Walsh's (2016) Family resilience theory

Family resilience is defined as the "characteristics, dimensions, and properties of families which help them to be resistant to disruption in the face of change and adaptive in the face of cri-

sis situations'' (McCubbin & McCubbin 1988, p.247). Walsh (2011) suggested nine processes that can help families (parents and dependent children) cope and manage when living with an adverse stressor, and promote psychological and emotional adaptation after the adverse event for the family (Walsh, 2016; Walsh & McGoldrick, 2013). The nine processes of family resilience are: (1) normalising the adverse situation within the home, (2) having a positive outlook surrounding the stressor, (3) fostering a sense of spirituality, (4) being flexible to reorganising structures when needed, (5) maintaining connected to each other, (6) availing of social networks when required, (7) clear communication within the home regarding the stressor, (8) having opportunities to share emotions openly and (9) shared decision-making (Walsh, 2016). It has been suggested family functioning is strengthened when these nine processes are fostered in families during an adverse situation (Walsh, 2016b).

In relation to the EOL experience when a parent of dependent children is dying from cancer, some of these processes have been reported as factors associated with coping for the family (Hanna et al., 2019). This has included: children's desire for clear information surrounding their mum or dad's declining heath *(clear communication within the home regarding the stressor)* (MacPherson & Emeleus, 2007; Park et al., 2017; Phillips, 2015; Tillquist et al., 2016), parents requirement of social networks to help with the practical aspects of parenting at EOL *(availing of social networks when required)* (Lundquist, 2017; Patterson & Rangganadhan, 2010), and opportunities for quality time together as a family when a parent is at EOL to create memories for the future *(maintaining connected to each other)* (Bugge et al., 2014; Hansen et al,, 2016; Hockley, 2000). Other literature has reported that when children are regularly informed of, and involved in the ill-parent's care at EOL *(normalising the adverse situation within the home)*, this enhances family cohesion and trust between the child and parents (Ellis et al., 2013). Further qualitative research may provide clarity surrounding how these nine processes associated with positive coping can be best supported in parents, when mum or dad is at EOL from cancer.

Kübler-Ross (1969) On death and dying

Kübler-Ross' model of death and dying reported five behavioural stages of patients at EOL concerning their illness: denial, anger, bargaining, depression and acceptance. It was later

reported that not all patients at EOL will go through all of these stages, and the stages are not linear as individuals may move between these states throughout the dying experience (Kübler-Ross & Kessler, 2005). In the denial phase, patients are suggested to feel shocked surrounding their poor prognosis and may reject the reality that they are dying. Studies within a systematic review that explored the experiences of parents and children when a parent is at EOL have often suggested barriers towards telling the children mum or dad is going to die included parents' denial surrounding the reality of the poor prognosis, or finding it too painful to tell them their parent is dying (Hanna et al., 2019).

Patients and their family's disbelief surrounding the reality of a declining health may be replaced by anger; which has been associated with feelings of bitterness towards others or a higher power such as God and, or feeling life is unfair (Kübler-Ross, 2011). Bargaining has been referred to as 'false hope', where patients make sense of their poor prognosis by negotiating with themselves or God for 'more time' (Kübler-Ross, 2009). It has been suggested the bargaining stage is associated with feelings of guilt and regret surrounding the past ("if only I had taken better care of myself") and for the future ("I won't see my children grow-up) (Martz & Morse, 2017). A patient and their loved ones may experience periods of depression with feelings of despair, isolation and hopelessness surrounding the declining health (Kübler-Ross, 2011). In the acceptance stage, patients and families are suggested to acknowledge death is the inevitable outcome. Literature has suggested that when patients or families 'accept' the reality of a poor prognosis, they are better able to make preparations for the death, such as advanced care planning, funeral arrangements or *'attending to other unfinished business in their personal life'* (Holland, 2014; Kübler-Ross, 2009).

Although the Kübler-Ross model of death and dying has been criticised surrounding its lack of theoretical underpinnings (Corr, 2019), literature has reported evidence of the five state behaviours from the death and dying model when a loved one is dying from a terminal illness (Corr, 2019; Holloway, 2007; Kuczewski, 2004; Prigerson et al., 2009; Saldinger & Cain, 2005). It is a useful model for this study to understanding the different reactions and responses of declining health towards EOL experienced by parents (Corr, 1993; Kearney & Hyle, 2014).

Collectively, the three theories considered relevant to this study (Lazarus & Folkman, 1984; Kübler-Ross, 1969; Walsh, 2016) will help the researcher in his understanding of how parents of dependent children cope and navigate the EOL experience, and support his interpretation of the data. The next section in this chapter will provide an outline of the research gaps.

2.5 Outline of research gaps

This chapter identifies a need for further research to better understand how parental support could be best facilitated, when a parent of dependent children is at EOL from cancer. While issues are explored throughout the chapter, key aspects requiring further exploration are outlined below:

1. There is a lack of understanding in the literature surrounding how parents manage daily family-life with their children, when a parent is at EOL from cancer. Exploration of what is happening within the family when a parent is dying from cancer can aid our understanding of what is required for and from parents, as they prepare and support their children for the death of mum or dad.

2. The literature lacks detail surrounding what language is helpful for parents, as they prepare to share information with their children surrounding mum or dad's cancer throughout the EOL period. There is a need to better understand how, when and what support is required by parents to communicate with their children, that mum or dad is dying from cancer.

3. Current literature has predominately explored the needs of mothers with advanced breast cancer who attend support groups and services, and have direct supportive involvement with family support workers or social care professionals (Hanna et al., 2019). There is a need for better representation and understanding of the needs of this population, beyond those parents who avail of support groups and services (Grande et al., 2006), to include fathers and those from low socioeconomic status and less well educated backgrounds.

4. There is a lack of understanding from the literature surrounding the role of HSCPs in providing supportive care to parents throughout the EOL experience concerning their children.

Although literature highlights providing this aspect of care may be challenging for HSCPs, it is unclear what they understand are the needs of this population, and what is being provided in practice. A better understanding of HSCPs' challenges in providing care to parents concerning their children may help identify key training needs for them in providing psychosocial support to parents at EOL.

2.6 Summary

This chapter provided an outline to key background literature surrounding the needs of parents and children when a parent is at EOL, which are discussed in detail in **Paper 1** (section 2.3). Pertinent background literature surrounding the role and challenges for HSCPs in facilitating support to parents at EOL concerning their dependent children was also provided. Relevant theories to the study were discussed and the chapter concluded with the need for further research, to better understand if, how, what and when support can be facilitated to parents, as they prepare their children for the death of mum or dad.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter outlines how the study was conducted, including the researcher's philosophical assumptions, research design, sample, sampling and recruitment, ethical considerations, data analysis, rigour and trustworthiness.

3.2 Philosophical assumptions: ontology, epistemology and methodology

Before conducting research, a researcher should consider their philosophical assumptions (Boyd, 2001; Creswell, 1998; Duberley et al., 2012; Scotland, 2012), which can guide how the researcher conducts the research (Scotland, 2012). Alignment between philosophical assumptions, chosen research design and aim and objectives is suggested to strengthen the rigour of a study (Boyd, 2001). A researcher's choice of research design is influenced by their ontological (what a researcher constitutes as reality), epistemological (the researcher's understanding of how knowledge can be acquired and communicated) and methodological (why, what, from where, when and how data is collected and analysed) assumptions (Creswell, 1998).

The researcher's ontological belief corresponds to the principle of relativism in that reality is subjective and varies between individuals (Baghramian & Coliva, 2019; Parahoo, 2014). The researcher's ontological resonation stems from personal experiences such as international travel, friendships and interactions with individuals from diverse backgrounds, as well as professional experiences such as a bachelor degree in psychology, employment and previous research projects involving ethnic and religious minorities.

Epistemologically, the researcher resonates that they are part of, and immersed in the research process through data collection and analysis (Perry, 1981; Scotland, 2012; Williams, 2000), appreciates differences between individuals (Goldkuhl, 2012; Williams, 2000) and reality should be discovered inductively (Goldkuhl, 2012; Scotland, 2012). The researcher identified with interpretivism (Scotland, 2012).

The researcher's philosophical assumptions are embedded in a social constructivism interpretative framework (Kukla, 2013; Parsons, 2010; Scotland, 2012). Together, with the research aims and objectives, the researcher's intent was to interpret the complexity (Kim, 2001; Kukla, 2012) and variation (Kim, 2001; Parsons, 2010; Scotland, 2012) of the needs of parents of dependent children when mum or dad is dying from cancer, and how best support can be facilitated to this population.

3.3 Research design

An interpretative qualitative inquiry was used to guide the conduct of the study (Merriam, 2002). This approach was considered most appropriate as it adopts elements from various qualitative designs that were helpful to address the objectives of this study and interpretation of the data, as well as alignment to the researcher's philosophical assumptions (Elliott & Timulak, 2005). The research needed to be conducted sensitively, as the topic of parents at EOL with dependent children has an emotional element, that may cause distress to the participants. Qualitative methods of data collection provided the researcher with greater flexibility than objective measurements, such as allowing him to adapt language regarding how questions were asked, and responding to emotional cues during data collection (Dickson-Swift et al., 2009).

In line with the researcher's philosophical assumptions, he acknowledged that participants' perceptions of the needs of parents at EOL with dependent children vary, depending on individual experiences and, or awareness of what is happening in the family when mum or dad is at EOL from cancer (Merriam, 2002; Yazan, 2015). The study aimed to explore this phenomena from different perspectives, to include parents at EOL and HSCPs. To provide a rich, in-depth understanding of the needs of parents at EOL, an interpretative qualitative design provided flexibility for the researcher to follow-up on identified categories between and within the sample groups throughout the data collection process (Merriam & Grenier, 2019).

An interpretative qualitative research design provided the researcher with a flexible method of data analysis (thematic analysis for this study), which was considered appropriate to explore the participants' experiences and perceptions, as well as highlighting similarities and differences between them (Nowell et al., 2017). Alongside this, an interpretative qualitative approach allowed the researcher to triangulate the data from the sample groups involved in this study to promote rigour and trustworthiness of the findings (Yazan, 2015). It was considered appropriate to triangulate the data to provide a richer understanding of the similarities and disparities, surrounding participants' perceptions of how best parents can be supported at EOL (Noble & Heale, 2019).

The next section will report on the participants included in the study.

3.4 Sample

Guided by the literature and research aim, four sample groups were involved in this study:

(1) parents at EOL,
(2) bereaved parents,
(3) HSCPs, and
(4) funeral directors

The rationale for these four groups will now be provided.

Parents (end of life and bereaved)

This study focused on the needs of parents when mum or dad was at EOL from cancer, and different perspectives needed to be gained. One perspective was with the ill-parent who was actually within the EOL phase, to understand how they were navigating the experience (to date). Having started to recruit mum's and dad's at EOL, it became apparent that accrual was slower than anticipated. Parents at EOL were predominately recruited from a family support service and hospice in Northern Ireland. Within these organisations, the gatekeeper (an appropriate staff

member within the organisation responsible to identifying those eligible for the study) often delayed sending the study invitation to parents, as they perceived the ill-parent was ‘not ready to take part’, or ‘required more time to adjust to their poor prognosis’ before participating. However, as can be expected with a poor prognosis, some ill-parents had died before the invitation was sent. Also, due to employment changes, one of the research sites did not have a consistent gatekeeper, and often meant parents at EOL eligible for inclusion to the study had died before being invited to participate. Alongside this, some parents at EOL who met the study inclusion criteria and expressed interest to taking part in the study ‘at a later date’ had died before participating.

To overcome these methodological challenges, another perspective was the inclusion of the bereaved parent after the death of the ill-parent. Reflecting on their experience as a bereaved parent will aid our understanding of what and when preparations were/should have been made before mum or dad died, to facilitate a better EOL and bereavement experience for the family (Holmgren, 2019; McClatchey, 2018). From the bereaved parents perspective, this knowledge will provide better insight as to how and when support should be provided to parents when mum or dad is at EOL from cancer (Park et al., 2015).

To promote accrual to the study, the researcher became a volunteer for 18 months at one of the research sites monthly bereavement support group for bereaved parents and dependent children. It was hoped that an established relationship between the researcher and gatekeeper would encourage and motivate them to invite parents to this study. This was also to aid the researcher’s insight to the experience for families when a parent of dependent children is at EOL from cancer, as he had limited exposure prior to undertaking this study. After a period of four months, the researcher facilitated the support group for bereaved teenagers. On reflection, it appeared that the researcher’s role as a volunteer at the research site did encourage the gatekeeper to invite parents to the study. This aligns with the suggestion that gatekeepers may be motivated to invite eligible participants to a study when it provides them with an immediate benefit (Choy & King, 2008).

HSCPs

Parents often require guidance and support from HSCPs surrounding how best to prepare their children for the death of mum or dad. Previous studies have predominately explored oncology nurses' perceptions of the needs of this population, whereas there is a wide variety of HSCPs that provide important clinical and non-clinical support when a parent is at EOL from cancer between acute and community settings. These include specialist (such as social workers, allied health professionals, clinical nurse specialists) and generalist (such as community and acute care nurses) HSCPs. A range of HSCPs were included to this study to better understand if, how and when supportive care is provided to parents at EOL concerning their children.

Funeral directors

Data from interviews with bereaved parents repeatedly referred to funeral directors as an instrumental source of support for the bereaved parent after the ill-parent had died. This was particularly evident in interviews where the period between receiving the poor prognosis and the death happening was over a shorter timeframe. Also, bereaved parents reported they sought advice and guidance from funeral directors concerning their children, as there were no other professionals available to them in the acute post death period. After discussion with the supervision team, it was then decided to expand the sample to include funeral directors. Funeral directors are a group who provide a service to individuals surrounding the organisation and delivery of a funeral in Western cultures. Funeral directors were included to capture from their experiences and perceptions, the needs of parents regarding their children in the acute post-death period; referred to as the immediate bereavement period. Also, to better understand the role of funeral directors in providing care and support to newly bereaved parents, when mum or dad has died from cancer.

The inclusion and exclusion criteria for the sample and their respective rationale are presented in Table 2.

Table 2: Sample inclusion and exclusion criteria

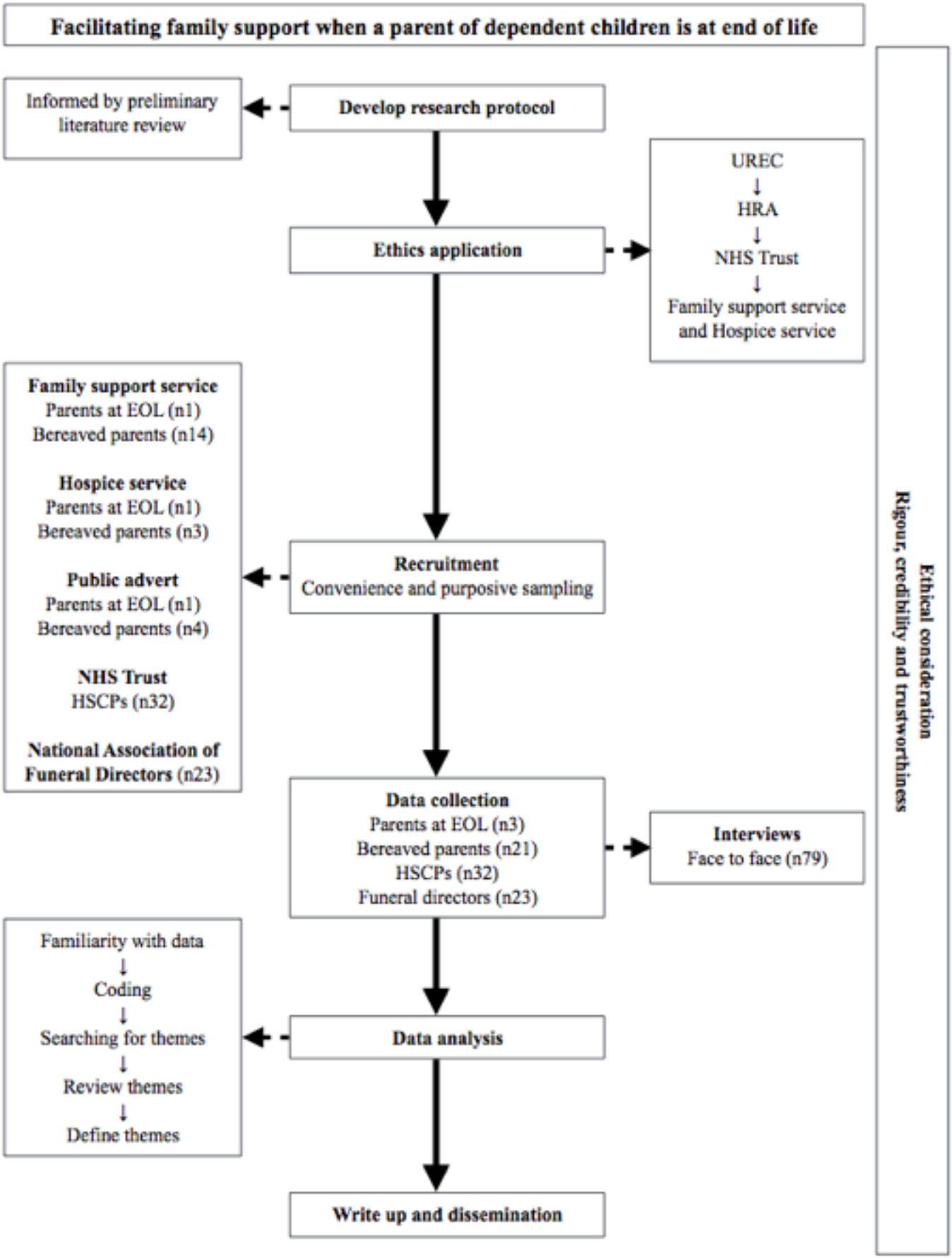
Sample group	Inclusion criteria	Exclusion criteria
Parents at EOL	Awareness of their advanced / terminal / palliative / life-limiting / incurable cancer. Considered physically well to participate. *Rationale: Various side-effects from treatments or a health decline may make it difficult or too demanding for parents to participate in the research. Ethical principle of non-maleficence.* Dependent children (<18 years old). *Rationale: An individual can be considered no longer a dependent child from the age of 18; were they become a 'young adult' (McDonagh et al., 2018). It would be expected young adults (ages 18-24) would have different challenges and needs, which was not within the scope of the current study.* Resided in Northern Ireland. *Rationale: This was a Northern Irish based study.* Ability to speak and understand English. *Rationale: Given the sensitive and distressing nature of the topic and the researchers limited knowledge of foreign languages, it was considered inappropriate to have translators part of the interview (Berman & Tyyskä, 2011). Cost for translation services was also a factor.*	Parents with gross psychopathology *Rationale: Ethical principle of non-maleficence*

Bereaved parents	Experienced the death of a co-parent to cancer. *NB: No limits were applied surrounding minimum period between death of ill-parent and inclusion to the study.* *Rationale: How an individual is coping in their grief is subjective. The emotions an individual experiences at three months post-death may be similar to that of nine years post-death (Bentley & O'Connor, 2015). To promote participant autonomy, parents should be provided with the choice as to when they feel is appropriate to take part in a study on a EOL experience of a loved one (Bentley & O'Connor, 2015).* *Upper-limits were usually between two to five years after the death for parents identified from the family support service and hospice. These were in line with both sites compliance to storage and handling of the parent's personal information.* *No upper-limits were applied to bereaved parents who volunteered to participate in response to the study's public advertisement. Ethical principle of autonomy.* Dependent children (<18 years old). *Rationale: Same as parents at EOL.* Resided in Northern Ireland. *Rationale: Same as parents at EOL.* Ability to speak and understand English. *Rationale: Same as parents at EOL.*	Parents with gross psychopathology *Rationale: Same as parents at EOL*

HSCPs	HSCPs who provide care to end-stage cancer patients as part of their clinical practice. This included, but not limited to, the district nursing team, palliative care team, allied health professionals (physiotherapists, speech and language therapists, occupational therapists) and clinical nurse specialists. *Rationale: This study was focused on the needs of parents of dependent children when one of them is at EOL from cancer. Patients (parents) are known to a diverse range of HSCPs when they have an end-stage cancer prognosis. To identify the support currently offered as part of routine clinical practice, it was considered appropriate to understand the experiences of a range of specialist and generalist HSCPs who work in both acute and community sectors with cancer patients who are at EOL.*	HSCPs who do not work within oncology departments or provide EOL care. *Rationale: They are not professionals who currently work with or necessarily have the experience with cancer patients who are advanced / terminal / palliative or incurable.*
Funeral directors	Funeral directors from private and public limited companies between rural and urban locations in Northern Ireland *Rationale: This was a Northern Irish based study. Alongside this, it was appropriate to consider differences in care and support (if any) provided from funeral directors between different sectors and locations in Northern Ireland.*	

An outline of how this study was conducted is presented in Figure 1. The next section of this chapter reports how participants were recruited to the study.

Figure 1: Outline of study design



3.4.1 Sampling and recruitment

The aim of the study was to better understand how parents could be best supported when a parent of dependent children is at EOL from cancer. Non-probability sampling procedures were deployed as there was no exhaustive population list available, and the sampling techniques were not random, but rather convenient and purposive (Acharya et al., 2013; Gentles et al., 2015; Kothari, 2004). Convenience sampling was appropriate in early interviews to provide the researcher with preliminary data, which guided subsequent interviews with purposive sampling techniques (Moser & Korstjens, 2018). Volunteer sampling techniques (Vehovar et al., 2016) were used in combination to recruiting parents to the study. This section will provide detail on the sampling and recruitment techniques used for the sample in this study.

Recruitment of parents (end of life and bereaved) to the study

Convenience sampling strategies were used to identify parents eligible to participate in the study. Initially, parents were recruited from a family support service in Northern Ireland. The family support service provides specialist support to help families cope with the impact of parental cancer. This includes one-to-one support with families to help prepare children for the death of a parent, and family bereavement groups.

Due to the challenges of recruiting parents at EOL to the study (as discussed earlier in section 3.4), and to have a better understanding of the experience for parents with dependent children when mum or dad was at EOL, bereaved parents were included to the study. To help with study accrual, and to promote a diverse sample of parents beyond those who are receiving/ received intervention from a family support service, the decision was made to recruit parents from hospice services in Northern Ireland that provide inpatient and outpatient care and support for patients and their families with a terminal illness including cancer. Accrual from one hospice service was successful, but despite attempts to add other hospice services to the study, this proved unsuccessful, mainly due to other research studies ongoing at these sites.

To recruit hard to reach families beyond support groups and services to the study, a public advert (in the form of a poster) was created (appendix A). The public advert was drafted by the researcher and the supervisory team. The content of the poster was assessed and validated for content, language and comprehensibility by members of the study's expert group, including a palliative care clinical nurse specialist and social worker, a bereaved parent and child (aged 14), and a family support worker. The public advert was published on three occasions (17.08.2018, 08.09.2018, 08.11.2018) as a half-page insertion to a leading national newspaper in Northern Ireland (appendix B).

The advert was also displayed in 183 public areas throughout Northern Ireland, to promote accrual to the study. The public areas included public notice spaces within clinical settings such as hospitals, local general practitioner practices and Macmillan cancer centers, as well as leisure and community centers, charity shops, public notice boards, gyms, supermarkets, sport clubs, churches and libraries.

Recruitment of HSCPs to the study

Initially, convenience sampling recruited HSCPs within one healthcare Trust in Northern Ireland. Purposive sampling techniques were then deployed to recruit a diverse range of generalist and specialist HSCPs, across acute and community sectors, whose role is to care for cancer patients at EOL at the same Trust.

Recruitment of funeral directors to the study

Funeral directors were initially identified using convenience sampling, to provide preliminary data to guide subsequent interviews. A purposive sampling method was then deployed to take into consideration funeral directors from private and public limited companies across urban and rural communities. The Northern Ireland section of the UK Funeral Directors Directory website assisted with the identification and recruitment to obtain such purposive sample.

The next section reports how eligible participants were invited to take part in the study.

3.4.2 Screening for eligibility

It was necessary to ensure that participants were screened for eligibility prior to inviting them to participate, to ensure that only those that met the study inclusion and exclusion criteria were included in the study. This section reports how the sample were screened for eligibility in this study.

Screening process of parents (end of life and bereaved) included in the study

Gatekeepers at the family support service and hospice had a significant role in identifying parents to be included in the study. From respective databases, gatekeepers identified the parents that met the study inclusion and exclusion criteria. Eligible participants were contacted via postal letter from the gatekeeper, with an invitation to participate in the study with the study information sheet (appendices C-D). An invitation letter (appendix E) was developed with the supervisory team, alongside the respective gatekeepers to invite the eligible parent to the study. The gatekeeper was considered appropriate to make initial contact with the parents regarding the study, as they likely had established rapport and trust with the eligible participants (Patel et al., 2003). Parents confirmed their willingness to participate via e-mail with the researcher.

Parents that expressed interest from the public advert made direct contact with the researcher, via e-mail or telephone. These parents were screened to ensure they met the study inclusion and exclusion criteria by the researcher via telephone or email (as appropriate). This was achieved by sharing an appropriately modified version of the *'what is the research study about'* section from the participant information sheet (appendix C/D, as appropriate). The parent usually confirmed if the study was appropriate to their circumstances, and expressed if they were still willing to be included in the study.

Screening process of HSCPs included in the study

The gatekeeper at the healthcare Trust was instrumental in identifying HSCPs eligible for inclusion to the study. The gatekeeper invited HSCPs to participate in the study by emailing them the study information sheet (appendix F). Interested and willing HSCPs confirmed their willingness to participate in the study with the researcher.

Screening process of funeral directors included in the study

Funeral directors were contacted via telephone by the researcher. They were provided with the study information from the participant information sheet (appendix G). Interested and willing funeral directors confirmed their inclusion to the study with the researcher via telephone.

The next section reports how data was collected in this study.

3.5 Data collection

Data was collected using qualitative semi-structured interviews. This approach was selected as most appropriate given the sensitive and emotional nature of the topic (Dempsey et al., 2016). The presence of others, such as through focus group methods to data collection, would unlikely have provided in-depth data on the personal, sensitive and emotive topic, or allowed the same exploration of individual experiences (Gill et al., 2008; Harrell & Bradley, 2009). Also, from a logistical perspective, focus groups would have been challenging to coordinate with HSCPs and funeral directors busy schedules (Lloyd-Evans, 2006). To prepare for undertaking the research, the researcher undertook workshops in qualitative methods of data collection and analysis. Prior to conducting the interviews, topic guides were developed to guide the discussions. Detail surrounding how the topic guides were developed in this study will now be discussed.

3.5.1 Topic guides

A topic guide was developed for each group included in this study, to maintain focus on the purpose of the study and stimulate discussions with the participants (Ritchie et al., 2013). The topic guides were informed by the literature, the researcher, the supervisory team and members

from the study's expert group. The topic guides consisted of an outline of categories and open-ended questions that were relevant to the study. Initial categories and open-ended questions were identified from the study's aims and objectives. Topic guides were iteratively modified throughout the data collection period to explore identified themes in subsequent interviews, between and within all sample groups (Ritchie et al., 2013). To validate the content of the topic guides prior to the interviews, the researcher engaged in role-play exercises with the supervisory team and other researchers (Arthur & Nazaroo, 2003). This contributed as part of the researcher's ongoing learning and feedback in qualitative methods of data collection. Piloting the topic guides helped with the identification of unclear questions. Suggestions were offered to enhance the clarity of the open-ended questions. Detail will now be provided surrounding the development and adaption of the topic guides for the four groups in this study.

Topic guides used in interviews with parents at end of life

To develop a sense of rapport between the researcher and participant, 'simple questions' were initially asked (Ryan et al., 2009). These were in relation to demographic details, such as understanding who lived in the home to include dependent children and their ages, and a spouse or partner. To maintain focus on the purpose of the study, this was followed by open-ended questions, framed around the study's objectives. For example, one of the objectives was to explore the experience for parents as they prepare their children for the death. This informed the first questions on the topic guide, such as 'tell me about when/where/who/what/how you told your children about your cancer diagnosis'. The topic guide was also informed by gaps in the literature. For example, literature suggests parents are often concerned about difficult questions the children may ask regarding the situation, which informed the open-ended question 'were you worried about questions the children might ask when you shared your diagnosis with them? If so, what questions'. Later open-ended questions in the topic guide were centered around the parent's thoughts of preparations for their children as death becomes more imminent, such as 'what do you think the children need to know and, or understand as the end comes very close?'. This topic guide can be found in appendix H.

Topic guides used in interviews with bereaved parents

Similar to the topic guide with parents at EOL, simple demographic details were initially collected followed by open-ended questions surrounding how they told their children that mum or dad was eventually going to die from cancer. The topic guide with bereaved parents included open-ended questions surrounding events throughout the EOL experience until the end of the immediate bereavement period. For example: 'tell me about how you prepared your children to say goodbye to mum or dad', 'tell me how you prepared the children for the actual death of mum or dad' and 'tell me about the days leading up to the funeral after mum/dad had died'. This topic guide can be found in appendix I. The topic guide was iteratively modified throughout the data collection process. Additional topics included advanced preparations for the future before the death, the presence (or lack) of the children as mum or dad was actually dying (children on the sidelines). A sample updated topic guide can be found in Appendix J.

Topic guides used in interviews with HSCPs

To establish rapport between the researcher and HSCP, 'simple questions' were initially asked (Ryan et al., 2009). These were in relation to demographic details such as exploring how many years clinical experience the HSCP had, and training received in relation to providing supportive care to parents regarding the children, when mum or dad is at EOL from cancer. Following this, guided by the study's aims and objectives, initial categories in the topic guide were framed around HSCPs' perceptions of the needs of parents at EOL regarding their dependent children. Open-ended questions included: 'what do you think is happening in families when mum or dad has a poor cancer prognosis', 'what do you think parents are sharing with the children regarding mum or dad's poor prognosis' and 'what has been your experience of caring for parents with dependent children when mum or dad is dying from cancer'. The topic guide was literately modified to explored identified themes throughout the data collection period. Additional sample topics included: shifting responsibility of providing supportive care to parents of dependent children when one is dying from cancer to other HSCPs, and supportive clinical envi-

ronments and emotional offloading of providing supportive care at EOL. The topic guide used with HSCPs in this study can be found in appendix K.

Topic guides used in interviews with funeral directors

To establish rapport between the researcher and funeral director, 'simple questions' were initially asked (Ryan et al., 2009). These were in relation to demographic details such as exploring how many years experience the participant held as a funeral director, and training obtained in relation to providing pastoral care to parents regarding the children in the immediate bereavement period, when a parent has died. This was followed by open-ended questions informed by the literature, interviews with bereaved parents, the study's aims and objectives and the study's expert group. This included: "can you tell me about your experience of working alongside families when a parent of dependent children has died from cancer?," "what do you see as challenging for families in the immediate bereavement period when a parent of dependent children has died from cancer?," and "what has been your professional role when providing a service to families in the immediate bereavement period when a parent of dependent children has died from cancer?". Additional topics included as interviews progressed included a family's struggle to sharing information with young children during the immediate bereavement period, and generational shifts impacting the immediate bereavement period when a parent of dependent children has died from cancer. This topic guide can be found in appendix L

The following section reports how the data was collected from the four groups in this study.

3.5.2 Conducting interviews with parents (end of life and bereaved) in this study

The researcher took responsibility in the recruitment and scheduling of all parent interviews. Parents who provided written consent (appendix M) to participate in the study were co-interviewed face-to-face by the second supervisor and the researcher. The second supervisor took the lead in these interviews. This was an ethical requirement of the study that interviews with parents would be conducted by an experienced clinician and trained qualitative interviewer. Also,

as part of the researcher's ongoing learning and development in qualitative research, acting as the observer and taking field notes (appendix N) provided the researcher the opportunity to learn how to conduct, coordinate and manage sensitive and emotional topics during qualitative interviewing. The researcher had the opportunity to follow-up on unexplored leads or cues after the main section of the interview was conducted by the second supervisor. The researcher provided written reflections on all interviews as part of their learning. Sample interview reflections are provided in appendix O. These reflections were discussed and appropriate feedback was provided at regular supervision meetings.

Interviews where facilitated at a location suitable for the parent. The majority of interviews took place at their home *(n19)*. Some parents had a preference for the interview in a neutral venue outside of their home such as their place of work *(n2)* or the research site they were recruited from *(n3)*. All interviews were audio-recorded and lasted between 60 - 120 minutes between February 2018 and February 2020.

Conducting interviews with HSCPs in this study

The researcher took responsibility in the recruitment and scheduling of all HSCP interviews. HSCPs that provided written consent (appendix M) to participate in the study were interviewed face-to-face by the researcher at their place work, at a time convenient for them. All interviews were audio-recorded and lasted between 20 - 50 minutes. Interviews were conducted between March 2018 and August 2019. The researcher had no prior relationships with the professionals. As part of the researcher's learning, written reflections were provided following each interview (appendix O). Feedback on reflections was provided as part of the researcher's regular supervision meetings.

Conducting interviews with funeral directors in this study

The researcher took responsibility in the recruitment and scheduling of all funeral director interviews. Funeral directors that provided written consent (appendix M) to participate in the study where interviewed face-to-face by the researcher at their place work, at a time convenient

for them. Some interviews were co-facilitated with the researcher's lead and second supervisor. The purpose of the supervisors co-facilitation was to provide on-going feedback to the researcher's development in conducting qualitative research, and to aid their connectedness to the study to ensure appropriate guidance was provided as the research progressed. As part of the researcher's learning, written reflections were provided following each interview (appendix O). Feedback on reflections was provided as part of the researcher's regular supervision meetings.

The next section of this chapter will report on the consideration of ethical issues in this study.

3.6 Ethical considerations

It was important that considerable attention was given to ethical implications in this study. This was due to the sensitive and emotive research area of death and dying (Sque et al., 2014), and more specifically when a parent of dependent children is at EOL from cancer (Dyregrov, 2004). Preparing children for the death of mum or dad is one of the most distressing challenges faced by parents at EOL (Hanna et al., 2019). Also, the provision of supportive care to parents at EOL is a stressful aspect of care for HSCPs (Franklin et al., 2019). It was necessary to ensure ethical issues were established from study inception surrounding the planning, conduct and reporting of the study, to protect participants from harm by taking part in the study. An overview of ethical considerations in this study are discussed under four headings: (1) obtaining ethical approval for the study, (2) participant's autonomy and informed consent, (3) non-maleficence (do not harm), and (4) confidentiality.

Obtaining ethical approval for the study

The University's Policy for the Governance of Research Involving Human Participants (Ulster University, 2015) and the Declaration of Helsinki from the World Medical Association (2009) guided the conduct of the study. Prior to commencing data collection, it is a requirement that ethical approval is obtained from appropriate organisations (Balen et al., 2006). In this study, ethical approvals were obtained from the Ulster University Research Ethics Committee (UREC,

17/SW/0155) (appendix P), the Health Research Authority (HRA) (appendix Q) and the participating research sites (appendix R). All documents were peer-reviewed prior to obtaining ethical approvals and suggestions and amendments were made where appropriate. For example, it was suggested to develop a support pack (appendices S + T) to signpost parents to relevant counselling services or support groups, if necessary in cases of distress. This seemed a useful and appropriate resource to provide parents with who were unaware, or asked about the availability of support services. Other reviewers' comments were addressed accordingly, such as a separate mobile phone number for interested participants to contact the researcher, rather than a personal phone number.

Participant's autonomy and informed consent

Informed consent is the process were a participant entered research voluntarily and provided written consent after being provided with the study information (Falagas et al., 2009). To promote autonomy in this study, when participants were invited to the study they received a letter from the appropriate gatekeeper (appendix E) informing them that participation was voluntary. Participants had to opt-in to the research, by confirming and initialing an eight item consent form (appendix M) concerning their understanding of the purpose of the study and voluntary participation. Prior to providing written consent, participants were provided with the opportunity to ask questions to the research team or gatekeepers. Additional opportunities to ask questions regarding the research were provided before the interview commenced, when the participant re-confirmed their participation. To the researcher's knowledge, all participants were in a position of power to provide informed consent (Neff, 2008; O'Neill, 2003).

Participants were not coerced to participate by the researcher or gatekeepers. Upon receipt of the study invitation letter by the appropriate gatekeeper, eligible participants were informed they would not be contacted again if they did not wish to take part. Alongside this, eligible participants were informed non-participation would not affect any current or future relationship with the research team, or the organisation they were identified from. A number of parents *(n27)*, HSCPs *(n7)* and funeral directors *(n15)* declined the invitation to participate in the study.

Often, gatekeepers suggested parents declined the invitation as it was reported too emotionally difficult to consider sharing their emotive story. Also, some HSCPs and funeral directors declined the invitation to participate as it was suggested they had a lack of time to be involved, or they perceived they had a lack of experience to meaningfully take part.

Non-maleficence (do not harm)

No intentional or purposeful harm should be caused at any stage of the research process (Martela et al., 2018; Moll, 2012). Participants were informed of their right to withdraw at any stage of the research, participation was not coerced, and participants were informed non-participation would not affect current or future relationships with the researchers, or the organisation they where identified from. Eligible participants were met at a venue most preferable to them and the interview was conducted in a private space.

A distress protocol was developed for conducting interviews with parents and professionals, outlining the steps to be followed if they expressed upset during the interview (appendix U). Emotions of upset were evident in interviews with parents, often occurring early in the interview. When parents expressed upset, interviews were temporarily stopped. It was important at this time to provide the parent with space and time to 'pause' and recollect their emotions. Also, providing them with reassurance that this is a sensitive topic and they do not have to continue any further with the interview. The interview only continued if and when the parent was willing, and orally expressed their interest to do so, to which all parents were. After the interview, parents reported it helpful and cathartic that they participated in the study, as it provided them the opportunity to talk about their feelings (Sheehan, 2010). A support pack was provided to parents after the interview (appendices S + T). Interviews with parents were co-facilitated with the researcher's second supervisor who had a wealth of experience in oncology nursing and qualitative research.

Opinions expressed by participants were respected by the researcher and appropriate use of non-verbals were applied (Newcomer et al., 2015). Complaints procedures were documented and provided to participants in the participant information sheet (appendix C, D, F, G). No complaints or issues occurred during the research process.

For researcher safety, lone-working policy procedures were observed (Pyer & Campbell, 2012; Wiles, 2012). The researcher 'checked-in and out' with the supervisory team when conducting interviews alone.

Confidentiality

Confidentiality is where the researcher is obligated to protect participant's information from unauthorised access, use, disclosure, modification, loss or theft (Kaiser, 2009). In this study, assurances of confidentiality were provided to participants throughout the recruitment and data collection process. Participants were informed that all personal information collected in the study would not be shared outside of the research team (researcher and supervisors). Participants were further informed that direct quotes may be used for publications, but no identifiable information would be used to protect their anonymity.

To ensure confidentiality in this study, interviews were conducted in private spaces. Often, interviews with parents were conducted when the children where at school, or in the evening time when the children were attending their extracurricular activities, to provide parents with space and privacy to share their 'story'. On occasions, children where present in the home during parent interviews. In these situations, the interview was usually facilitated in a space of the home with a closed door.

To protect the researcher, participants were contacted using a mobile phone with a number specific to the study or a University email address. Any messages or emails containing personal information such as the participant's home address were removed at earliest convenience.

Data was stored on password protected files on a password protected P.C. only accessible by the researcher. Both passwords were different and made up of unique characters, letters and symbols. Data protection procedures are in place to destroy of all data after 10 years (Carey, 2018). Consent forms were kept in a locked filing cabinet in a locked office with CCTV.

The next section of this chapter reports how data was analysed in this study.

3.7 Data analysis

Braun and Clarke's (2006) thematic analysis framework was considered the appropriate form of analysis for the data collected from bereaved parents, HSCPs and funeral directors. Data collected from parents at EOL in this study was analysed using narrative analysis, which will be later discussed in section 4.2. This section will report how thematic analysis was conducted on the data from bereaved parents, HSCPs and funeral directors.

Thematic analysis is not tied to any particular epistemological or theoretical perspective. It was used for this study as it is a flexible method useful to exploring individual's experiences, perspective and opinions, as well as similarities, differences and unanticipated insights (Braun & Clarke, 2006; Nowell et al., 2017). Deployed as an inductive method, the process of identifying themes in the study were derived from the data (Maguire & Delahunt, 2017). This is in line with the researcher's philosophical assumptions. Braun and Clark's (2006) framework provided a six-step guide to conducting thematic analysis: (1) become familiar with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) define themes and (6) write-up. The six-steps were not linear and was possible to move forward and back between them (Maguire & Delahunt, 2017; Nowell et al., 2017). The steps are now discussed in relation to this study.

Step one: become familiar with the data

The first step involved immersion into the data and reading and re-reading of the transcripts, field notes (appendix N) and reflections (appendix O), to understand and appreciate the depth and breadth of the content (Braun et al., 2015; Nowell et al., 2017). The audio-recordings were transcribed verbatim by the researcher. A professional transcriber assisted in the transcription of some HSCP interviews due to time constraints. The transcripts were verified against the audio-recordings to ensure validity. Listening and re-reading of the transcripts enabled the researcher to become familiar with the large volume of data, before progressing to step two, or if further interviews were required to follow-up with leads not fully explored. This happened in interviews with HSCPs, where listening and re-reading of the transcripts enabled the researcher to identify some categories that were not fully explored; necessitating the need for additional inter-

views. During this step, the researcher made brief notes of early impressions of the data to document their reflective thoughts of what was 'coming out of the data'; see appendix V.

Step two: generate initial codes

This step allowed the researcher to organise the data in a systematic and meaningful manner (Braun et al., 2015; Nowell et al., 2017). Coding enabled the researcher to further understand the data, by separating the data into small *chunks* that had meaning (see appendix W for sample audit trail) (Nowell et al., 2017). The researcher had ideas regarding what the codes would look like from step one. As an inductive process, open coding was used, and codes were developed by marking similar phrases or words in participants' narratives. For example, in interviews with bereaved parents, they often talked about how 'emotionally difficult' it was to consider telling the children mum or dad had a poor cancer prognosis; resulting in the code 'emotional readiness'. Similarly, in interviews with HSCPs, it was often perceived they, the HSCP, had a lack of 'time' to meaningfully engage with parents at EOL regarding their dependent children; resulting in the code 'lack of time'. Other codes were developed by identifying meaning from the participant's narrative. For example, in interviews with bereaved parents, phrases such as 'I was the one that told the kids'; resulted in the code 'well parent - sharing information' or 'sharing information - pre-existing role' depending on the family situation. To ensure rigour and trustworthiness, all codes were independently analysed and discussed with the researcher's supervisory team (Mackieson et al., 2019).

The coding process was aided using computer assisted qualitative data analysis software, NVivo v12. NVivo provided the researcher with a simple, easy to use platform to manage the large volume of data and organise the coding process. As a novice user, the researcher undertook a training workshop to learn how to use the software.

Step three: search for themes

At this stage, the researcher tried to make sense of the codes by searching for themes, and identifying where some of them fitted together, see appendix X for sample audit trail (Nowell et al., 2017). For example, several codes in the funeral director data set related to ways of 'involv-

ing the children in the delivery of the funeral' such as 'graveside - handshakes', 'funeral service participation' and 'funeral - choosing music'. At this stage, the researcher experienced challenges with overlap of codes between themes. For example, in the HSCP data, the researcher had codes 'detachment of work-home life' and 'emotionally-charged conversations' in the theme 'emotional impact of engaging', which over-lapped with another theme 'treating the primary problem'. At this stage, it was helpful for the researcher to use manual methods of sorting codes into themes. This included note-taking and small pieces of paper with code descriptions. See appendix X for sample audit trail. Themes were then discussed through critical dialogue with the supervisory team to help further define themes. This is discussed in step four.

Step four: review themes

Given the overlap and large volume of themes created in step three, it was necessary for the researcher to review, modify and re-develop the themes. It occurred to the researcher at this stage that some of the themes identified in step-three were relatively descriptive, however provided the researcher with a more manageable and focused data set to understand the 'unfolding story' (Nowell et al., 2017). For example, the researcher organised the HSCP data codes into themes representative of barriers and facilitators. The researcher reflected that this was a basic level of analysis and did not provide an in-depth understanding of HSCPs' provision of supportive care to parents at EOL concerning their dependent children. Also, in the bereaved parent data, the researcher limited the data into themes that reflected the study's objectives, which did not capture the richness and complexity of the experience for parents of dependent children when mum or dad is at EOL from cancer (see appendix X for sample audit trail). The researcher identified a need to reorganise the codes into themes that would offer deeper conceptualised meaning (Clarke et al., 2015). After reflection and discussion with the researcher's supervisory team, the researcher identified new themes from the codes that provided a 'richer' story of the data, see appendix Y for a sample audit trail. To ensure rigour and trustworthiness, themes were verified and refined through critical dialogue with the researcher's supervisory team (Nowell et al., 2017; Thomas & Magilvy, 2011).

Step five: define themes

Step five involved a refinement of the themes and 'identify the essence of what each theme is about' (Braun & Clarke, 2006, p.92). It was important for the researcher to identify overarching themes, and understand how they interact and relate to the sub-themes (Braun & Clarke, 2006; Clarke et al., 2015). It became apparent in the funeral director data that some themes had repetitive information, and by merging them into one theme provided an in-depth account of the experience for families when a parent of dependent children has died in the immediate bereavement period. This resulted in the removal of three sub-themes: 'the distress and uniqueness of the situation' 'importance of language' and 'the need for reassurance and guidance' into one broad theme: 'funeral directors' perceptions of challenges experienced by families surrounding the time of parental death'. To determine suitability and comprehensibility, overarching and sub-themes were verified and refined through discussion with the researcher's supervisory team.

Step six: write-up

Once themes were verified, results were written up for dissemination in academic peer-reviewed journals and abstracts for international conferences. The researcher ensured the write-up of results provided a coherent, concise, logical and interesting account of the data (Nowell et al., 2017). Direct quotes were included in the final reports to aid understanding and demonstrate the prevalence of the themes (Braun & Clarke, 2006; Nowell et al., 2017). To ensure rigour and trustworthiness, the findings were linked back to the literature (Nowell et al., 2017) and opportunities to add to the literature were taken in the discussion (Clarke et al., 2015; Nowell et al., 2017).

This section reported how data was analysed in the current study. A sample audit trail of the data analysis process can be found in appendixes V-Y. The next section of this chapter will report how steps were taken to ensure rigour and trustworthiness in the study.

3.8 Rigour and trustworthiness

It is important that findings are recognised as familiar, so they can be understood by researchers, practitioners, policymakers and the public (Morse, 2015; Nowell et al., 2017). In doing so, it convinces others that the findings are worthy of attention (Nowell et al., 2017). To demonstrate reflexivity in findings, the researcher clarified their philosophical assumptions at study inception (see section 3.2) and recorded reflections throughout the data collection process (Darawshes & Stanley, 2014; Dodgson, 2019) (appendix O). To examine trustworthiness in qualitative research, Lincoln and Guba (1985) defined four key concepts: credibility (how true the findings are), transferability (how applicable the findings are), dependability (how consistent the findings are) and confirmability (the evidence). Steps taken to ensure trustworthiness in relation to each of these components in this study are now discussed.

Credibility

Credibility in qualitative research addresses the *fit* between the participants views and the researcher's representation of them (Connelly, 2016; Cope, 2014; Tobin & Begley, 2004). A number of techniques were deployed to ensure the findings of this study were credible. A mix of participants were included in the study (parents at EOL, bereaved parents, HSCPs and funeral directors) and triangulation of sources ensured representative samples of these populations were recruited to the study. This included a diverse range of HSCPs who work in oncology and EOL care between acute and community settings, funeral directors who work in private and public limited companies across rural and urban locations, and hard to reach parents outside of support groups and services (Cope, 2014; Korstjens & Moser, 2018).

The study's expert group assisted in the development of the topic guides to ensure the study's aims were achieved, and were involved in discussions of identified themes throughout the data collection period. Quotes were used to provide 'thick descriptions' in the reporting of the data (Connelly, 2016; Korstjens & Moser, 2018). The researcher did not come a healthcare background, which contributed towards the control of bias in understanding HSCPs role in providing supportive care to parents at EOL concerning their children. Findings were peer-validated with the researcher's supervisory team, to help control for the researcher's subjectivity and bias in the

reporting of findings (Birt et al., 2016). Finally, to enhance the credibility of the study, findings from parents (EOL and bereaved), HSCPs and funeral directors were triangulated in an overall discussion of the findings (Chapter 5).

Transferability

Transferability refers to the degree findings could be applicable to other contexts or settings (Cope, 2014; Houghton et al., 2013). To achieve transferability in this study, the researcher provided thick descriptions of the participants and research process (Korstjens & Moser, 2018; Nowell et al., 2017). Descriptions were provided (where appropriate) on the following: the study setting, study inclusion and exclusion criteria, interview topics, the context participants were recruited from, sample size, level of education and training, professional occupation, years of professional experience and demographics, to include gender, cancer site, socio-economic characteristics, age and gender of children.

Dependability

Dependability refers to the consistency of the research results if the study were to be replicated in a similar context using the same procedures (Guest et al., 2012; Houghton et al., 2013). One strategy to achieving dependability in this study was an audit trail throughout the data collection (figure 1) and analysis (appendices V-Y) process (Korstjens & Moser, 2018; Nowell et al., 2017). The researcher documented reflective thoughts after each individual interview (appendix O) and throughout the data analysis process (appendix V) (Guest et al., 2012; Korstjens & Moser, 2018). These reflections provided the researcher with a transparent documentation of his thinking, and a trail as to how interviews and data analysis progressed; promoting research reflexivity (Connelly, 2016; Nowell et al., 2017). An audit trail was kept on key methodological decisions within the study, as documented in minutes of supervision meetings (appendix Z) (Guest et al., 2012). To further enhance dependability, the researcher documented the recruitment strategy with details on the sample selected (Guest et al., 2012; Nowell et al., 2017).

Confirmability

Confirmability refers to the integrity of findings (Connelly, 2016; Houghton et al., 2013; Watkins, 2012). Guba and Lincoln (1989) suggested confirmability is established when credibility, transferability and dependability are achieved. To further achieve confirmability in this study the researcher acknowledged his philosophical assumptions (section 3.2) (Connelly 2016). To further control for bias and demonstrate reflexivity the researcher maintained open-minded during data collection (i.e. through open ended questions and following up on leads in the topic guides, appendices H-L) and data analysis (i.e. the need to recode and modify themes following discussions of the data with the researcher's supervisory team, appendices W-Y).

3.9 Summary

The study was conducted using a qualitative research design informed by the researcher's philosophical assumptions and the study's aims and objectives. 79 participants were included in the study, comprising of parents at EOL *(n3)*, bereaved parents *(n21),* HSCPs *(n32)* and funeral directors *(n23)*. Ethical considerations were observed throughout the study. A thematic analysis framework guided the analysis of the data and steps were taken to ensure rigour and trustworthiness of the findings. The findings of the study are presented in Chapter Four.

CHAPTER FOUR: FINDINGS

4.1 Introduction

Overall, 79 participants were included in this study, comprising of parents at EOL, bereaved parents, HSCPs and funeral directors. This chapter reports the findings from these four groups. First, the findings are presented from the parents at EOL included in this study. Due to challenges of recruiting parents at EOL, only three dad's at EOL were involved in this study. These findings will be presented through narrative analysis. The second part of this chapter reports the findings of bereaved parents' perceptions of the needs of parents with dependent children, when mum or dad is at EOL from cancer. This has been written up in paper format as **Paper 2** of the study and is under peer-review at Palliative Medicine. The third part of the chapter reports the findings of the role of HSCPs in facilitating care and support to parents concerning their dependent children when mum or dad is at EOL from cancer. This has been written in paper format and published in Psycho-oncology **(Paper 3)**. The fourth part reports the findings of the experiences of funeral directors when a parent of dependent children has died in the immediate bereavement period. This has been written in paper format and published in Death Studies **(Paper 4).**

4.2 Findings from parents at end of life included in this study

The intention of this study was to recruit parents at EOL to explore their experiences of parenting dependent children when mum or dad was at EOL from cancer. Unfortunately, due to recruitment challenges only three parents at EOL were involved in this study. Sample characteristics of these three parents are reported in Table 3. A narrative analysis (Campbell et al., 2019) was considered the most appropriate method of reporting this data, as it is concerned with reporting the 'story' of individual experiences, when *'insufficient data has been collected to allow theme or discourse analysis'* (Wong & Breheny, 2018). The three narrative accounts are reported below.

Table 3: Characteristics of the three parents at EOL that participated in the study

Variable	*N*	Variable	*N*
Participant (parent)		**Recruitment source**	
Father	3	Hospice service	1
Mother	0	Public advert	1
		Family support service	1
Cancer Site			
Pancreatic	1	**Socioeconomic details**	
Lung	1	**Highest level of completed education**	
Bowel	1	Secondary level (GCSE/A-Level)	2
		Skills based qualification	1
Marital status			
Divorced	2	**Employment status**	
Married	1	Self-employed, part-time	1
		Unemployed	2
Gender/Age of children			
Boy, 0-11 years old	0	**Source of household income**	1
Boy, 12-18 years old	2	Employment	2
Girl, 0-11 years old	0	Social security funding	
Girl, 12-18 years old	3		

Interview 1: Brett

Brett was a 54 year old single father raising a teenage son and daughter. He was diagnosed with pancreatic cancer two years ago, and was receiving various treatments up until two months ago. He described pain surrounding the sharing of the news with the children that he had cancer; suggesting a delayed disclosure in telling them the poor prognosis for around six weeks. Some of the reported obstacles to telling the children that he was going to die included a fear of how to handle difficult questions from the children such as ‘when are you going to die’ and uncertainty surrounding the reactions from the children; especially his daughter with concerns regarding the potential of self-harm. Brett reported that when he shared the news with them that he had a poor prognosis, they were told ‘I’ve got cancer of the pancreas and it’s not looking good’. There appeared to have been a wall of unspoken thoughts and feelings between Brett and the children regarding the situation, as he suggested he had not asked them how they were feeling surrounding the reality of his poor prognosis. Brett suggested he did not want to talk about his

declining health and impending death with the children as he 'felt guilty at leaving them without a dad'.

As a divorced parent, Brett reported taking the predominant lead in parenting responsibilities and described concerns surrounding the future of his children's welfare and 'who would look after them after he was gone'. However, Brett reported a lack of preparations for the future in relation to guardianship for the children and suggested 'crossing that bridge later'. Alongside this, there appeared to have been a broken relationship between Brett and his ex-wife, and he suggested a lack of communication between them surrounding his declining health and the impact of the situation on their children.

"have I thought about when I'll not be here, not really, well, I suppose just that the kids will be looked after. I don't think their mother will take much to do with them but somebody, I hope somebody will take them"

Brett described his desire to create lasting memories for the children before he died, with reported conscious efforts of taking photos at what was perceived as '*probably the last Christmas together'*. Also, he highlighted his desire to maintain routine despite his declining health. However, Brett did describe finding it *'exhausting'* carrying out parenting responsibilities as a result of his cancer. It was reported there were a lack of social networks available within the family to help with the practical aspects of parenting, and the teenage daughter had been reported to be taking time off school each week to help him with household chores.

"if I'm not fit to get up and do things for myself she'll stay at home and look after me and help with cooking my meals and the wee fella's, and she'd clean about the house too"

Finances appeared to have been an issue for Brett, with reported concerns surrounding stability in securing social housing and benefits from social security services. It was reported helpful when a clinical nurse specialist provided him with advice surrounding the benefits he was

entitled to, and sourced funding for home heating oil. The same nurse specialist was reported to advise Brett *'to put your affairs in order for the future'*, which he perceived was in relation to *'putting away a few pound for the funeral'*.

Interview 2: Andre

Andre was a 52 year old father living with his two teenage daughters and wife. He reported the children were aware of his ill-health, but suggested they were unaware death would be the inevitable outcome of his condition. Andre suggested he desired to tell them the reality of the poor prognosis, so his children would not grow up with feelings of guilt or resentment towards him or his wife. However, it was suggested the mum, the well-parent, wanted to delay sharing the reality of the situation with the children, perhaps until there would be clearer signs of Andre's health deteriorating towards EOL. Alongside this, Andre suggested feeling unable to talk with his partner surrounding his desire of telling the children he was going to die, for a fear of causing pain and upset to her:

"I would like to tell them [children] the truth of it because I don't think I am being fair to them. it is a wee bit like the elephant in the room, but I am not just sure that Joan [well-parent] and myself are at the same place about telling them. I know she is very concerned about telling them, but we have not talked about it together"

Andre reported efforts of forward-planning for the future, such as sorting out the finances, property and taxes. Although these tasks were described as time-consuming, he reported how this was important to him to ensure the stability and security for his family for after he would die:

"I am more busy dying than I ever was living. But I don't want Joan [well-parent] to worry about these things for after I've died. she might not see it that way now, but you could only imagine the legal battle she would have to go through otherwise"

As a result of declining health, Andre described a *'lack of opportunity to get out of the house';* however he also shared feelings of satisfaction surrounding spending quality time together as a family through the usual happenings in the home. This included mealtimes and playing board games together at the weekend:

"I don't get too far these days as metal Mickey always has to be with me, but I do enjoy the time I spend with the girls in the evening, and mealtimes are always an important family time for us. I would say I have come to cherish that time together a bit more"

Andre described a desire to write a letter for each of his children for their 21st birthday. He reported purchasing specific stationary two months ago, but then went on to say how he was finding it too painful to actually think about *'not being around for them in the future'*. Also, he reported how he feared *'writing something in such a way that the wrong meaning would be taken from it'*. It was suggested that the letters would be written *'later';* perhaps when his health would deteriorate:

"to be honest, I'm not sure in my mind if now is the time to write them. I feel that writing them makes it become real, and I'm not at that downward spiral yet. that's part of my reluctance to commit writing to paper"

Interview 3: Colin

Colin was a 44 year old single dad living with his teenage son, Dylan. The interview with Colin was quite short in nature as many of his responses to the open-ended questions and probes were 'I don't know'. Colin did report telling Dylan he had cancer shortly after receiving the poor prognosis, as he suggested he 'would know something was different'. However, Colin reported that he had not yet shared with Dylan that he was eventually going to die from his poor prognosis. Colin suggested withholding information surrounding the reality of his poor prognosis from Dylan, as he was hopeful treatment would prolong life:

"I didn't really see the need to tell him that straight away, I mean there's still a chance with treatments that I am going to beat this"

Alongside Colin's hope for living longer, he reported forward planning for the future, to secure the financial stability for Dylan *'if death happened sooner rather than later'*. This included making a will and updating life-insurance policies:

"I hope I will be around for a long time, but I don't know when death is going to come knocking on the door, so it's good to be prepared just incase"

Colin reported a desire to spend time outside of the home with Dylan while he was still well, to make memories for after he had died, but suggested he was unsure what this would look like:

"when we're in the house we're in separate rooms. I would like us to both get out and have some father-son bonding together, but I'm not really sure what that is yet. it's just something I've been thinking about"

The next section of this chapter reports the findings of the bereaved parents in this study, presented in paper format.

4.3 Findings from bereaved parents included in the study (Paper 2)

This sections reports the findings of the bereaved parents included in the study. Overall, 21 bereaved parents were recruited to the study between 5 weeks and 6 years after the death of the ill-parent. Semi-structured interviews were conducted with parents, recruited from the general public, a family support service and a hospice in Northern Ireland. Findings highlighted that parents are often living in parallel worlds throughout the EOL period. In one world, parents are 'living in the moment' with their family, remaining hopeful treatment will prolong life, alongside trying to adapt as the illness unfolds. The other world presents as intermitted glimpses that death

is approaching, shadowed with painful emotional concerns surrounding their children and the future. At the end, death rapidly and suddenly approaches, characterised as suddenly ‘falling off the cliff’ and placing significant demands on the well-parent. Eight sub-themes were identified, further categorised into five broad themes: (1) emotional readiness to share the unfolding poor prognosis with the children, (2) parallel worlds: living in the moment and intermittent glimpses that death is approaching, (3) striving to live by focusing on the hope from treatment and that derived from spiritual faith, (4) running out of time - falling off the cliff and (5) how best to support parents across the EOL continuum. This paper has been submitted to Palliative Medicine for peer-review.

‘Living in parallel worlds’ – bereaved parents’ experience of family life when a parent with dependent children is at end of life from cancer

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Abstract

Background: When a parent of dependent children (<18 years old) is at end of life from cancer, this has a profound impact on the family. Children less prepared for the death of a parent are more susceptive to poorer psychosocial adjustment in later life. There is a lack of understanding from the literature surrounding what support parents require, and how they navigate this end of life experience.

Aim: To explore bereaved parents' experience and needs for families when a parent is at end of life from cancer with dependent children.

Design: In-depth semi-structured qualitative interviews were conducted with 21 bereaved mothers and fathers, identified from the general public, a family support service and hospice. Data were analysed thematically.

Results: Parents often live in 'parallel worlds' throughout the end of life period. In one world, 'living in the moment', cherishing the ordinariness of family life, remaining hopeful treatment will prolong life, whilst adapting as the illness unfolds. The other world presents as 'intermitted glimpses that death is approaching', shadowed with painful emotional concerns surrounding their children and the future. At the end, death rapidly approaches, characterised as suddenly 'falling off the cliff'; placing significant demands on the well-parent.

Conclusions: Amidst challenges, clinicians should provide parents with clear information surrounding a poor prognosis, so families can plan and prepare for parental death. There is a need for healthcare professionals to engage, encourage and equip parents, as they prepare their children throughout the end of life experience for the inevitable death of a parent.

Keywords: Parents, cancer, qualitative research, end of life, children

What is known about the topic?

- End of life is an especially stressful and disruptive experience for families to navigate with dependent children (<18 years old).
- Parents of dependent children often feel ill-equipped and uncertain how best to prepare and support their dependent children for the impending death of a parent from cancer.
- Parents' desire and need psychological support and guidance from health and social care professionals (HSCPs) on preparing their dependent children for parental death but in reality, this is often lacking.

What this study adds?

- Parents are living in 'parallel worlds' throughout most of the end of life period; mainly characterised by making the most of everyday ordinariness in an attempt to maintain a sense of normality and provide stability for the children, with only intermittent glimpses into the other painful world that parental death is approaching.
- Lack of clear, realistic information on prognostic disclosure; coupled with hope of life-extension from evolving treatments contributes to a lack of advanced planning and preparing children for parental death.
- Postponement of advanced planning by parents is impacted by emotional distress and pain to confront the grim reality of impending death; reconciling that such preparations will occur nearer to the time of death, but more never taking place.

Implications for practice, theory and/or policy

- Clinicians should provide parents with clear and realistic information surrounding the reality of their advanced cancer, with honest disclosure on prognostic estimates from available treatments.
- Family-centred communication should be seen as a process, with HSCPs encouraging and equipping parents to start the difficult conversations soon after receiving the poor prognosis, to

avoid crisis management when the ill-parent is actively dying or throughout the immediate bereavement period.

- To facilitate a better end of life and bereavement experience for the whole family, parents should be encouraged to forward plan shortly after receiving a poor prognosis and create memories for the future by capturing life as it naturally happens.

1. Introduction

It is estimated that 20% of patients who are of a parenting age, with cancer, experience death whilst parenting dependent children (<18 years old, hereafter referred to as children).[1] The end of life trajectory for families is highly disruptive and unpredictable when a parent of dependent children is dying from cancer.[2] For the purpose of this study, end of life is when a person is not on a curative pathway and expected to die from cancer within twelve months.[3] Challenges that are likely to confront parents throughout this end of life period include a reduced availability for parenting; changes to parental roles; heightened distress in relation to preparing and supporting their children for the impending death of their parent; and, or financial implications for the family.[4,5]

One of the intricate and complex challenges faced by parents with a poor prognosis is how to best prepare and support their children throughout this end of life experience.[5] When children have an understanding of the dying process and are prepared for the death of their parent, they show quicker adjustment than those children who are not informed.[6] Conversely, children who lack support and involvement during their parent's end of life experience are more susceptive to psychological difficulties throughout childhood, to include a decline in education and increased levels of guilt and mistrust.[7,8] Unfortunately for some, these negative effects can be prolonged, with heightened susceptibility to adversities in later life, such as substance abuse and mental health issues.[9] The benefits of open communication between parents and children at end of life are clear, in that it maintains and sustains the parent-child relationship and mediates for such adversities.[7]

A recent systematic review by Hanna et al.[4] highlighted parental obstacles in preparing children for the inevitable death of a parent from cancer at end of life. These include but are not limited to parents (both ill and well-parents) lack of readiness to accept the parent's declining health and, or hope for life-extending treatments. While parents often require supportive guidance from HSCPs surrounding how best to prepare their children for the inevitable death of a parent,[4] literature highlights such family-centred care can often be inadequate in routine clinical practice.[5,10] To better understand how and when family-centred cancer care can be best facilitated and provided, there is a need to gain an improved understanding of how parents managed the end of life experience with their children and the needs of this population.

Aims and objectives

Through interviewing bereaved parents, this study aims to explore the experience and needs of parents with dependent children, when their mum or dad is at end of life from cancer. Through the lens of bereaved parents, the objectives of the study are:

1. to explore how parents perceived they managed family life, when mum or dad was at end of life from cancer.
2. to explore communication between parents and their children when mum or dad was at end of life from cancer.
3. to explore how parents who have children prepared for the death of mum or dad, when a parent was at end of life from cancer.
4. to explore how parents could be best supported as they managed family life, when mum or dad is at end of life from cancer.

2. Methods

A qualitative design using semi-structured interviews was employed for the current study. The study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[11]

Participants

Twenty-one parents participated in the study between April 2018 and February 2020. Convenience sampling identified participants from the general public, a family support service and hospice throughout Northern Ireland, UK. The family support manager and social worker at respective organisations identified those eligible for inclusion (Table 1) from their databases, and directly mailed potential participants the study information sheet and consent form. No further introduction, explanation or follow-up was initiated. A total of 18 out of 35 parents did not respond to the invitation to take part in the study.

Volunteer sampling techniques were also used to help with study accrual and representations of hard to reach families beyond support groups and hospice services.[4] A public advert was developed by the research team plus the study's expert group, which consisted of a palliative care social worker and clinical nurse specialist, a family support worker and a bereaved parent and child (aged 14). The advert was published on three occasions in a national newspaper and displayed in 183 public spaces, including clinical settings, leisure and community centers and supermarkets in Northern Ireland. Four interested and willing parents confirmed their inclusion to the study with the fourth author [J.R.H.] by e-mail or telephone. Written consent was obtained at the time of interview.

Data collection

A topic guide was developed, guided by the literature alongside the research and expert group (Table 2). The guide was modified as categories were identified to enable follow-up in subsequent interviews. Interviews were completed when no further categories were identified. Interviews were conducted face-to-face by the first author [C.J.S], who was an experienced qualitative researcher and senior cancer nurse specialist, and the fourth author [J.R.H] who was an academic researcher; neither of whom had prior relationships with the participants. Interviews were audio-recorded and lasted between 60-120 minutes at a venue convenient to the participant

[home (*n*16), work (*n*2), support service site (*n*3)].

Data analysis

Audio-recordings were transcribed verbatim and managed using NVivo v.12 to facilitate analysis using Braun and Clarke's thematic analysis framework.[13] To ensure rigour, credibility and trustworthiness, all authors read the transcripts. However, the first author [C.J.S] and fourth author [J.R.H] read and reread the transcripts to gain a sense of each parent's story, then independently coded the data, detailing inductive descriptive codes, using the participants' own language when possible. Through an iterative process of reviewing and discussing data with the research team [C.J.S, E.McC, E.R.B, J.R.H], early ideas identified in the process of coding became more focused and refined, and patterns in participants' experiences were identified, generating initial themes. At joint meetings, the research team discussed, reviewed and refined themes.

Ethical considerations

Parents opted-in to the research, and were made aware of their right to withdraw and that this would not impact upon any current or future care they may receive from the hospice or family support service. A distress protocol was established to protect parents from risks of emotional distress, and a support pack was provided to parents as part of the study's debrief. Data protection procedures were observed and assurances of confidentiality were given. Ethical approvals were obtained at institutional and national levels [REC:17/SW/0155].

3. Results

Twenty-one bereaved parents were recruited, 12 who were mothers and nine fathers. Parents were identified from a family support service *(n14)*, a hospice *(n3)* and a public advertisement *(n4)*. Participants were between five weeks and six years after the death of the parent *(mAverage = 14.6 months),* but mostly (*n15)* less than eighteen months from the death of the parent. Sample characteristics are reported in Table 3.

When the ill-parent was living with advanced cancer, they often underwent different treatments to help limit the progression of their cancer. For the majority of families, the ill-parent's health gradually declined throughout most of the end of life experience, until a point in time when their body became less responsive to treatment; evidenced by rapid signs of disease progression and notable physical deterioration at the end. In contrast, for a few individuals, the illness trajectory was limited to a period of weeks or days from accessing healthcare to the parent's death. The data below are representative of the former longer disease trajectory, as presented by most family's situation. Figure 1 constructs this continuum, highlighting some of the key interconnected complexities and needs for parents of dependent children, when mum or dad is at end of life from cancer. Eight sub-themes were identified, further categorised into five broad themes: (1) emotional readiness to share the unfolding poor prognosis with the children, (2) parallel worlds - living in the moment and intermittent glimpses that death is approaching, (3) striving to live by focusing on the hope from treatment and that derived from spiritual faith, (4) running out of time - falling off the cliff and (5) how best to support parents across the end of life continuum.

Theme 1: Emotional readiness to share the unfolding poor prognosis with the children

As reported by the bereaved parent, both the ill and well-parents (hereafter referred to as parents when referring to both) most distressing concern when diagnosed with a poor prognosis was for their children. Most parents highlighted that initially it was too painful to consider telling the children mum or dad's cancer had returned and they would eventually die from their cancer. There was an evident 'need to get their head around it first' before sharing with others, never mind the children. Following a period of 'time to process' the distressing information of incurable cancer, parents' timing and attempts to communicate this news with their children varied considerably. Barriers that precipitated delay in disclosure was parents' belief their children should not be made aware their mum or dad was going to die until the parent was 'evidently deteriorating'. They perceived this was protecting and shielding their children from unnecessary and prolonged pain and upset. In other circumstances, parents felt it was best to wait until key events had passed, to include the child's school exams or key celebrations such as birthdays and Christmas. On occasions, there appeared to be tension between the parents in relation to the tim-

ing of sharing the information with the children. More often, there was a greater sense of urgency from the well-parent that the children were informed of this difficult news that the cancer was advanced and progressive.

"I started to get frightened. the cancer was spreading at a pace faster than we anticipated. but he was just Mr. Positive, whereas I suddenly was panicking and thinking I'm going to be left here on my own with three kids." [parent interview 17]

Generally, at some level the well-parent wanted to be involved in the communication of this significant news. Their reasoning was twofold; as a means of protecting and minimising their spouse's distress, but cognisant they would have ongoing parenting responsibility and wanted to influence information provision and assess the children's reactions. After this initial conversation with the children that mum or dad's cancer had returned, there were other significant conversations between the parents and the children, which proved emotive and harrowing as the cancer progressed and death was approaching. Of note, the timing of these conversations was predominately influenced by parents' emotional readiness to share the news and not the children's developmental age.

"W*ent back on Monday morning and the cancer had spread to the brain. So that was another massive blow. You know you're slipping down, but each slip is a massive blow." [parent interview 20]*

Parents were also uncertain how they were going to manage parenting responsibilities as the ill-parent's health declined. Even more so, they worried how the death of a mum or dad would psychologically impact the children. Also, bereaved parents reported feeling already worried about the possibility of raising the children on their own. However, they did not want to openly share these concerns with their spouses as they felt this would cause them further distress.

Theme 2: Parallel worlds - living in the moment and intermittent glimpses that death is approaching

Many parents were living in parallel worlds throughout most of the end of life experience, characterised by mainly choosing to live in the moment. Parents' savored everyday life, with only occasionally thinking about the impending death. While parents reported knowledge that death was the inevitable outcome, it was considered too painful to confront this reality continually or make comprehensive forward plans for the ill-parent's death. Often, everyday life was encapsulated by the following sub-themes: (1) life goes on - adapting to the poor prognosis in the family, and (2) making the most of ordinariness - capturing life as it happens.

Sub-theme: Life goes on - adapting to the poor prognosis in the family

Within the last year of life, it appeared important for parents to maintain previous parenting roles, routine and responsibilities in the family, despite the physical constraints imposed by the ill-parent's cancer. This included the ill-parent continuing with aspects of parenting they could practically and emotionally manage, such as helping with homework, sorting out playdates and making lunches. This was driven by an ardent effort to protect the children, by creating a sense of routine, normality and security for the children. This also provided opportunities for the ill-parent to 'parent'. Also, parents wanted their children to continue with their usual activities such as going to school, attending their sporting events, and spending time with friends as they perceived this lessened the emotional distress for their children.

"So she picked the kids up and taking them home again. She loved all that. That's it being mummy. That's all she ever wanted to be was a mummy. So as long as mummy was in the car, you know it's fine. Mummy's still there. To be fair, as long as mummy is still here, I can go and get a hug anytime I want and that's good" [parent interview 02]

In spite of endeavoring to minimise disruptions to family routines, sometimes it was necessary for parents to adjust routines throughout the end of life experience, especially if the ill-parent required hospitalisation. Maintaining routine became more effortful and less achievable as

the ill-parent's health was declining. Nonetheless, parents demonstrated immense resourcefulness that enabled them not only to adjust, but adapt, so they could continue with some daily routines even when close to the parent's death.

"Bert said to me 'tomorrow can I use the desk in your bedroom because I want to do some work' and he said 'this isn't bad I'll sit up here'. And he died the next day. Those weeks seemed to condense into hours" [parent interview 19]

Often, as the ill-parent became increasingly unwell and death was imminent, they still continued to be 'involved' in everyday family life. Although doing less 'practical' parenting, their role remained nonetheless significant, such as listening to the child's school day, sharing advice and providing instructions. Being in the same room as the child enabled a 'parental' presence, which provided connectedness with their child:

"Sally [ill-parent] would have sat in her wee chair so they [children] could have sat watching TV while Sally was there. Maybe with her eyes closed sleeping or whatever, but Sally was still there, and in their [children] eyes involved" [parent interview 02]

Sub-theme: Making the most of ordinariness - capturing life as it happens

As parents anticipated future disruptions and losses, there was an evident keenness to do more activities with the children. Therefore, when the ill-parent felt 'well enough', family-related activities and outings were 'engineered' to optimise these experiences.

"If he was having a good day, I'd have said come on we're going down to the Bay or we'd go here or go there" [parent interview 04]

Once parents processed that death was hastily approaching, despite their fears and sadness they intentionally focused on cherishing everyday happenings within the family, such as going for a walk or getting an ice-cream. Many more photographs and short videoclips were taken,

motivated by an effort to 'capture the moment' and have these as lasting memories for the children. Alongside this, celebrations such as birthdays and achievements were reported as more consciously experienced, with parents absorbing and 'finding joy' in these moments:

"Once you get through that phase, he's not going to do, I just wanted to make sure that Maurice [ill-parent] and Abbey [child] had memory things and the simplest wee things. You know he loved getting the lego out and him and her. And taking photographs without them looking. Just so she has things that are like daddy did that with me' [parent interview 07]

Some parents did write letters for the future, but often these memory activities commenced only as death was hastily approaching. Due to physical and cognitive cancer-related limitations, they were often 'incomplete' or 'filled with mistakes'. In reality, most ill-parents had not 'got around to doing them', as it was too painful for them to 'put in writing' the certainty of not being around for the children in the future. Other parents felt the recommendation by professionals to produce memory boxes or related items, created a background pressure on them.

"Chiara had written a list of things to do, but she didn't get through them all. She had hoped to do memory boxes and things like that, but I think it was too painful for her to be quite honest. It was too emotionally difficult" [parent interview 14]

Capturing the moment was important, irrespective of the ill-parents' physical location. For ill-parents who spent some time at end of life in an inpatient palliative care unit, there was an intense appreciation to 'capture the moments' and continue with 'parenting', despite mum or dad's declining health. When HSCPs suggested and facilitated activities with the children during visits, such as going to a café or cinema, or 'party time' in mum or dad's room, these were welcomed. Similar family-centred activities were not reported when parents were in the acute hospital setting.

"In Marie Curie, we had party dates with the kids, or went out somewhere and went to the cinema or went out to a restaurant or café" [parent interview 10]

Theme 3: Striving to live by focusing on the hope from treatment and that derived from spiritual faith

Although parents reported knowledge that mum or dad's cancer was advanced with no potentially curative treatment options, some remained hopeful that the ill-parent would either survive the cancer or have many more years to live. This is discussed under two sub-themes: (1) hope in treatments: current and novel, and (2) hope derived from spiritual faith.

Sub-theme: Hope in treatments: current and novel

Parents were often offered and subsequently pursed a series of treatments; when one failed, another was considered. It appeared each treatment option ushered in hope and optimism, especially novel immunotherapy treatments, that they would 'give them more time'. A number of parents could be described as having excessive optimism in modern cancer care, and were still placing hope in the cancer being successfully treated, and not causing mum or dad's demise. Some parents maintained this hope right up to the final weeks and days of life.

Often, it seemed to be the ill-parent who was placing more hope in effective, life-extension from treatment. While the well-parent was also hopeful treatment would prolong life, they appeared more realistic that death was edging nearer as a result of clear indications of the parent's declining health.

"Dominique [ill-parent] would have said it's okay we're getting treatment and everything's stable. And everyday we're getting closer to them coming up with something new. He [ill-parent] thought he would beat this, so I couldn't be negative" [parent interview 11]

Sub-theme: Hope derived from spiritual faith

During end of life, a few parents had a strong religious or spiritual belief that the parent would be healed from cancer, and for some this thinking remained until their actual death. Such hope meant a lack of advanced planning. For other parents, there appeared to be a comfort derived from their spiritual faith, reporting no fear of dying, and a hope in mum or dad going to 'a better place' after their death.

"Dave [ill-parent] had a really strong faith and so he didn't really have a fear of death. he believed he would go to heaven. He wasn't scared about that which I think really helped" [parent interview 21]

Theme 4: Running out of time - Falling off the cliff

For variable periods of time, it appeared parents coped by adjusting and getting through the ups and downs of treatments, with 'home life going on as usual'. Then the ill-parent declined very quickly, moving hastily to the 'dying period'; typified in days or short weeks. Often, this was triggered by an apparent complication from treatment or from more rapid disease progression. For many, this led to a hospital admission and the parent's death. At this pivotal point in time, parents did get a sense they were 'running out of time' as a family, describing the feeling like 'falling off the cliff'.

"Suddenly he nose-dived over Christmas. Boxing day, he made it out on Boxing day and he headed out with his cousin and went down to The Inn [local restaurant]. Came home and managed to sit up with everyone, but basically he nose-dived on a daily basis and died early January" [parent interview 05]

Sub-theme: Getting through the last weeks and days: Focus on the ill-parent with children on the sidelines

As death was rapidly approaching, the ill-parent was reported as struggling, often both emotionally and physically. They had reduced independence, needing help with personal care and, or parenting responsibilities.

"He [ill-parent] hated Nia [child, 5 years old] seeing him being so weak and so emotional. We had to get him dressed and stuff and Nia would have come in and helped me put his socks on. It used to break him that she had to do things" [parent interview 01]

Despite parents' devoted focus on the needs of children throughout the end of life trajectory, when death became imminent, children appeared to be on the side-lines. There was an obvious lack of parenting capacity from either parent, as the well-parent's attention was focused on the 'dying partner'. Input from close social networks (mainly family members) was frequently necessary to help with the practical aspects of parenting at this juncture. Some parents highlighted the challenge that hospitals, unlike the hospice presented, due to strict visiting periods that coincided with times of basic family routines. This included picking the children up from school, homework, evening mealtime and bedtimes. However, in the last few days when the parent was actively dying in the home or hospice, parents wanted 'uninterrupted' time with their close family unit and limited visits from 'outsiders'.

Theme 5: How best to support parents across the end of life continuum

As bereaved parents reflected on the end of life experience, they reported a need for supportive input from HSCPs to help facilitate necessary preparations before the death of the ill-parent. However, family-centred care had not always been evident during their family's end of life journey. These are discussed under three sub-themes: (1) honest information on prognosis from HSCPs, (2) guidance on preparing the children for mum or dad's death, and (3) encouraging parents to forward plan for the future.

Sub-theme: Honest information on prognosis from HSCPs

While the clarity of information provided by HSCPs on the ill-parent's prognosis varied, most parents wanted to be honestly and realistically informed that the cancer had progressed and death was inevitable. During significant conversations with HSCPs, parents focused not only on the language used, but also their emotional cues. On reflection, parents reported that HSCPs

hinted and ‘hid behind’ phrases like ‘making the most of time left’; ‘what’s important is quality of life’; or ‘I’ll make a referral to the hospice’. Through the lack of prognostic disclosure, some families consequently felt unprepared and ‘launch padded’ into the ‘active dying’ phase of this end of life trajectory. Many parents stated that it should be HSCPs leading the conversation on prognostication (not having the parents asking), and HSCPs should provide clarity regarding ‘time left’; especially when death is approaching in the final weeks and days.

“I could see Darryl [ill-parent] deteriorating. She [palliative care nurse] said we are talking days. That was like, gutted. I had no idea and he died on the Monday… I was thinking months, maybe two, three months” [parent interview 16]

However, providing information on prognostication appeared complex, highlighted by occasional tension when only one parent wanted the conversation about life-expectancy and the other did not. Also, how this sensitive information was perceived and received was further influenced by the parents’ personal faith, or hope in treatment for extending life, acknowledging the need in these situations for a skilled communicator.

Sub-theme: Guidance on preparing the children for mum or dad’s death

It appeared most parents trudged through a period of living with advanced cancer, ‘nervously aware’ of the need to tell the children mum or dad is going to die, but postponing telling them until mum or dad’s health rapidly deteriorated at the end. At this juncture, many parents had a heightened awareness of the need to tell the children. Having reached this ‘crisis’ point, there was now much uncertainty and an abundance of concerns surrounding how best to tell them mum or dad is going to die very soon.

Some parents reported receiving helpful support when they sought guidance from HSCPs, or when the healthcare team signposted them onto a family support service. However, most parents reported a lack of supportive care from HSCPs regarding the children and suggested their involvement was mostly providing physical care to the ill-parent. On reflection, be-

reaved parents stated preparing their children for the death of mum or dad was an 'isolating' experience, and it would have been useful if HSCPs had guided them on parenting throughout this end of life period. Primarily, parents wanted words and language from HSCPs on how to share this distressing news with the children, and how best to answer difficult questions of how and when mum or dad would die.

"What on earth am I going to tell the children. I needed guidance. What's the right approach to tell the children. And I just got so frightened suddenly because the cancer had gone into the brain and it was in the bones" [parent interview 09]

Telling the children mum or dad was eventually going to die was an especially emotive and difficult experience for parents. For those that 'took it on', they considered it a great relief once 'it was out there'. Parents who reported not telling the children until after the parent had died, reflected it may have been helpful if they had had more open and honest conversations with them before the death:

"I don't think it would have been as hard to tell on the day (of the actual death) if I would have prepared her (daughter) you know, daddy hasn't got too long left" [parent interview 15]

Sub-theme: Encouraging parents to forward plan for the future

At the commencement of the end of life period, some parents reported engaging with practical arrangements for the future, which proved helpful. This included making a 'will', as a means of securing the family's future. Whilst it was perceived that other more personal and intimate preparations and conversations surrounding wishes for the future would happen 'nearer the time of death'; in reality, most parents had limited meaningful conversations surrounding future family-life. Mainly, the reason for postponement was these conversations were deemed too painful, plus having the conversation acknowledged the stark reality of death approaching.

When future plans such as financial matters were not addressed pre-bereavement, the bereaved parent reported a cumbersome process in the months following the death. While discussions surrounding the future were reported as emotionally challenging, the well-parents advocated the importance and helpfulness of forward planning for the future before the opportunity passes by. This included managing practical matters such as finances, 'wills', and passwords on accounts, as well as conversations surrounding personal elements such as funeral wishes and future aspirations for the well-parent and children.

"We really didn't get into those conversations and I guess that is one of my regrets. But when someone is fighting so hard, how do you say 'well what are we going to do when you die'. So the only thing I made sure was that we got her will signed off" [parent interview 13]

4. Discussion

Findings highlighted parents were often living in parallel worlds throughout the end of life period, which appeared to impact their readiness to prepare their children for the impending death of the ill-parent. In one world, it was important for parents to adapt to the unfolding prognosis within the family, in their attempt to maintain some sense of normality,[14] and to provide stability for the children.[15,16] Also, parents had pinned hope that treatments may prolong life,[17,18] with further hope in technological advances of finding a cure.[19] Alongside this, in another world parents were experiencing emotional pain and concern as they considered the impact of the inevitable parental death on their children[4] and the well-parent. For many parents, it was too painful to contemplate telling their children mum or dad was eventually going to die from cancer. [4] An important factor that appeared to have impacted parents ability to prepare the children for the inevitable death of mum or dad was a lack of clear prognostic information from HSCPs surrounding the reality of the unfolding situation.[4,20,21] Parents also felt ill-equipped regarding the appropriate language to use as they prepare to have the conversation with the children regarding their mum or dad's cancer being incurable, and preparation for the actual death.[22] Furthermore, some parents did not want to acknowledge and accept the reality that the ill-parent would die from the cancer. Thereby, telling the children would somehow made the dying 'real'. For those

families that postponed disclosure that mum of dad's cancer was incurable, there was a sense of 'crisis management' and desire for HSCP input and guidance when the parent was rapidly declining, coined as 'falling off the cliff'.

While parents keenly wanted support and guidance from HSCPs concerning how best to prepare their children for the death of mum or dad, it was suggested that this was often lacking. HSCPs mainly directed care towards the physical needs of the ill-parent to include symptom management. Similar findings have been reported by Hanna et al.[5] and Franklin et al.[10]. It may be suggested a lack of supportive care from HSCPs to both parents regarding the children impacted the parents' ability to prepare them for the death of mum or dad.[4] This can be especially poignant when the well-parent is not involved in end of life conversations with HSCPs, or when HSCPs' attention is solely directed towards the ill-parent's physical needs; neglecting person-centred care. Evidence suggests that HSCPs' provision of supportive care to both parents at end of life regarding the children can help reduce the tensions between them surrounding how best to support their children when mum or dad is at end of life from cancer.[23] However, HSCPs have reported this as an emotionally challenging aspect of their role and often feel ill-equipped to provide this care in practice, necessitating a requirement for training to facilitate family-centred care in routine care.[5,10]

Literature reports parents' desire to spend quality time together as a family when mum or dad is at end of life from cancer to create memories for the future.[4,24,25] In this study it was important for parents to capture family-life (mentally and tangibly with photographs and video-clips) as it was naturally happening, savoring the moments, and to make the most of the everyday ordinariness as a key form of memory making. This was instead of creating elaborate plans such as going on foreign holidays.[26] While literature suggests parents are often encouraged by HSCPs or family support workers to engage in activities such as memory boxes,[27,28] it was reported by most parents as too emotionally difficult. It may be suggested that encouraging parents to engage in memory activities, particularly in hospice and acute settings as the ill-parent's health deteriorates at end of life creates an unnecessary pressure, and is too intrusive for parents at an emotion-

ally difficult time.[29] Rather, to facilitate memories for the future, it may be helpful if parents were encouraged to make the most of ordinary everyday activities, taking and capturing each day as it comes, and do the things they enjoy most as a family when the ill-parent still feels well.[19]

During the parent's final weeks of life, there was an essential need to have significant input from extended family members, necessitated by the 'absence' of the ill-parent and the well-parent, whose focus was directed to caring duties or spending quality time with the ill-parent;[30,31] often in the hospital or hospice. It could also be purported that this practical support was necessary due to fixed visiting periods in the acute setting, which often coincided with school and meal times for the children. There is a need for flexible visiting arrangements when a parent of dependent children is at end of life.

More often these close social networks facilitated the practical aspects of parenting, providing reassurance that the children were being looked after and the child's routine was less impacted.[4] While it may not always be possible, families should be encouraged to maximise their social networks to help with the practical aspects of parenting as the ill-parent's health deteriorates. However, as highlighted in the findings, parents' desire for uninterrupted time when mum or dad is actively dying to facilitate quality family time together.[32]

It was suggested forward planning for the future facilitated ease for the bereaved parent following the death. Similar findings have been reported within the bereavement literature.[33] For other parents, it appeared postponement of advance planning was impacted by finding it too painful to prepare for not being around for the children or spouse,[14] and feeling such preparations would occur closer to the time of death.[20] However, this often did not happen, as the ill-parent became too unwell as their health rapidly deteriorated at the end. Other explanations include parents' fear of talking about the future would cause pain and upset to their spouse;[34] therefore feeling avoidance of such conversations would protect them from emotional distress.[35] To facilitate a better bereavement experience, there is a need for HSCPs to encourage parents to make necessary preparations and openly communicate about the future soon after receiving the poor progno-

sis;[36] as death often occurs sooner than expected and parents may be less able to make necessary preparations at that time.

Limitations and directions for future research

Bereaved parents included in this study are representative of those from two-parent or 'significant adult' families. It is unclear how single parents and those with complex family set-ups navigate family life, when a mum or dad is at end of life from cancer, despite efforts to gain broader representation of sample by public advert. The sample recruited participants within Northern Ireland, being one of the four countries within the United Kingdom, which could be described as a more culturally homogenous population.[37] Nonetheless, in recent years Northern Ireland has become increasingly secular and ideologically more diverse.[38] The interviews were conducted retrospectively and the bereaved parents' perspectives may have been impacted by their experiences from the period following death. Future studies should consider longitudinal research in this area that follows families (parents and children) throughout the end of life trajectory.

5. Conclusion

Through the lens of bereaved parents, this study highlighted the complex and highly emotive experience for parents of dependent children, when mum or dad was at end of life from cancer. There is a need for parents to be encouraged to make significant preparations shortly after receiving a poor prognosis. This includes informing the children of the parent's poor prognosis and inevitable death, as well as managing practical and financial matters for the future. To help facilitate these preparations, HSCPs should be providing parents with clear prognostic information surrounding the reality of their poor prognosis, with necessary updates as death becomes imminent. Alongside this, HSCPs should be providing the 'language' for parents to engage with honest and age-appropriate conversations with their children, informing them that mum or dad is going to die.

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Table 1: Participant eligibility criteria for inclusion to the study

1. Experienced the death of a co-parent to cancer. NB: No limits were applied surrounding minimum period between death and inclusion to the study. Rationale: How an individual is coping in their grief is subjective and the emotions an individual experiences at three months post-death may be similar to that of nine years post-death.[12] Upper-limits were up to five years following the death for those parents identified from the family support service and hospice. These were in line with both sites compliance to storage and handling of the parent's personal information. No lower or upper-limits were applied to parents who volunteered to participate in response to the study's public advertisement.
2. Dependent children (<18 years old).
3. Resided in Northern Ireland.
4. Ability to speak and understand English.

Table 2: Semi-structured topic guide used to guide the conduct of the study

Initial topics based on the literature, research aim and objectives and expert group.

1. Exploration of family life between receiving the incurable diagnosis until the parent's death.
2. Communication between parents and children from receiving the incurable diagnosis, until the parent's death.
3. Parent's emotional readiness to share the incurable diagnosis with the children.
4. Exploration surrounding how parents prepared their dependent children for the death of mum or dad.
5. Emotional, practical, and other (unmet) needs throughout the experience from receiving the incurable diagnosis until the death.

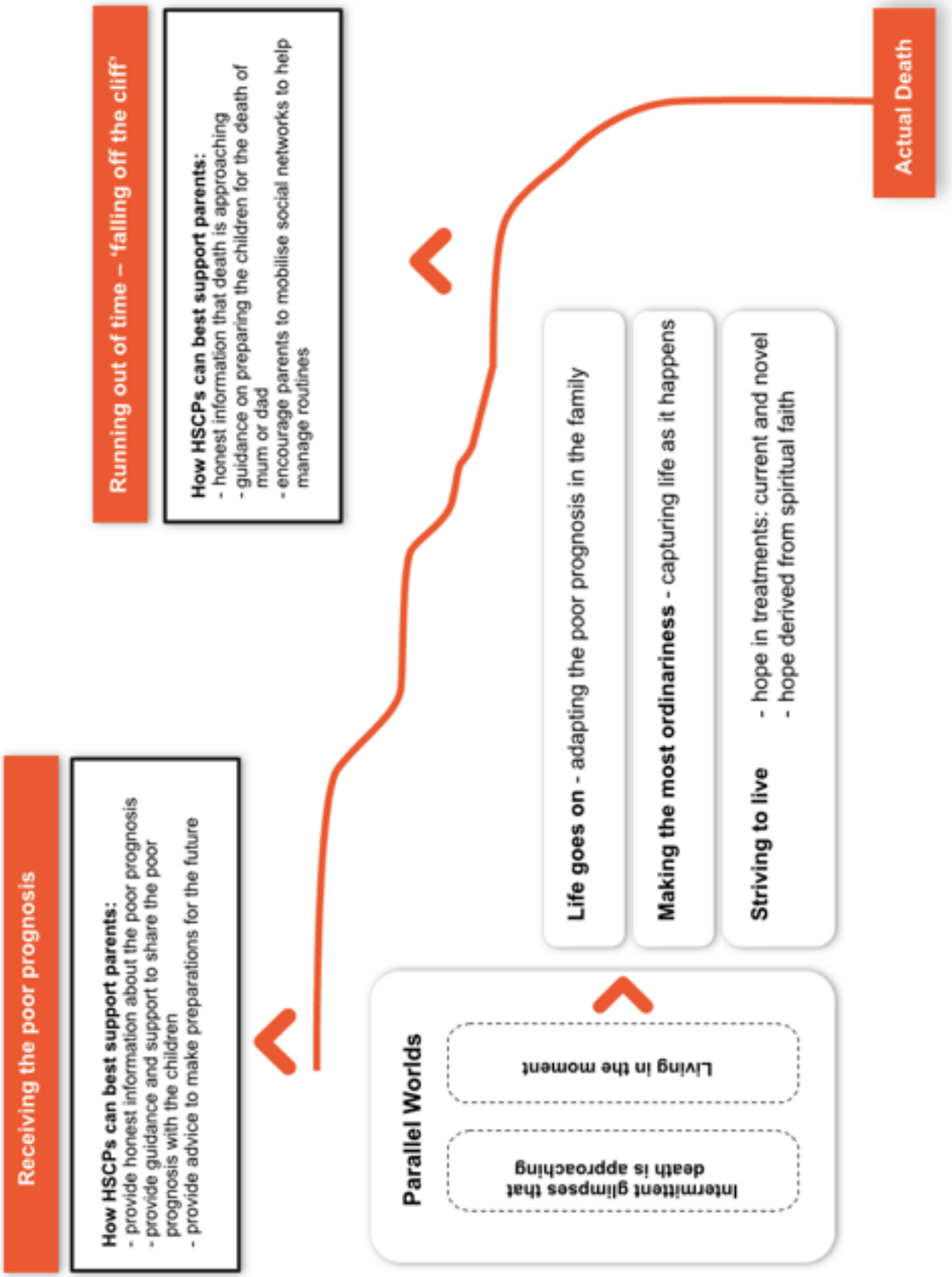
Sample of additional topics following identification of initial categories.

1. Pre-existing parental roles in sharing information with the children surrounding mum or dad's incurable diagnosis and declining health.
2. Exploration of parent's engagement (or lack of) in memory activities.
3. Navigating parental responsibilities and extended support network when the ill-parent was imminently dying.
4. Forward planning for the future.

Table 3: Sample characteristics of the parents included in the study

Variable	*N*	Variable	*N*
Participant (parent)		**Recruitment source**	
Father	9	Hospice service	3
Mother	12	Public advert	4
		Family support service	14
Cancer site			
Pancreatic	2	**Place of death**	
Lung	1	Home	5
Bowel	1	Hospice	7
Breast	2	Hospital	9
Head and neck	1		
Glioblastoma	3		
Melanoma	2	**Socioeconomic details**	
Renal	1	**Highest level of completed education**	
Esophageal	3	Secondary level (GCSE/A-Level)	6
Angiosarcoma	1	Skills based qualification	2
Liver	2	Bachelor's degree	11
Ovarian	2	Master's degree	2
Marital status at time of death	2	**Employment status at time of death**	
Married	1	Full-time work	5
Partner		Part-time work	2
		Leave of absence	10
		Maternity leave	1
		Unemployed	3
	15		
Gender/Age of children	7	**Main source of household income at time of death**	
Boy, 0-11 years old	19	Employment	7
Boy, 12-18 years old	12	Statutory sick pay	9
Girl, 0-11 years old		Statutory maternity pay	1
Girl, 12-18 years old		Social security funding	4

Figure 1: End of life continuum when a mum or dad with dependent children is dying from cancer



4.4 The role of HSCPs in providing supportive care to parents concerning the children, when a parent of dependent children is at EOL from cancer (Paper 3)

This section reports the findings of the HSCPs included in the study. Overall, 32 specialist and generalist HSCPs across acute and community settings were recruited to this study, to explore their experiences and perceptions of providing supportive care to parents regarding their children when a parent is dying from cancer. Semi-structured interviews were conducted with HSCPs within one Trust in the UK. HSCPs' perceptions of the challenges faced by many parents when a parent is dying from cancer included parental uncertainties surrounding if, when and how to tell the children that mum or dad was dying, the demands of managing everyday life when a parent is dying from cancer, and preparing the children for the actual death of their mum or dad. Many HSCPs felt ill-equipped to provide supportive care to parents at EOL concerning their children, and suggested the provision of supportive care to parents at EOL concerning the children the role of another professional. Five sub-themes were identified further categorised into two broad themes: (1) hurdles to overcome when providing psychological support to parents at end of life and (2) support needs of families for the challenging journey ahead. This paper has been published in Psycho-Oncology.

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PAPER

WILEY

Providing care to parents dying from cancer with dependent children: Health and social care professionals' experience

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Abstract

Objective: Parents often feel ill-equipped to prepare their dependent children (<18 years old) for the death of a parent, necessitating support from professionals. The aim of this study is to explore health and social care professionals' (HSCPs) experiences and perceptions of providing supportive care to parents regarding their children, when a parent is dying from cancer.

Methods: Semi-structured qualitative interviews were conducted with 32 HSCPs, including nurses, allied health professionals, social workers and doctors from specialist or generalist roles, across acute or community sectors.

Results: HSCPs' perceptions of the challenges faced by many families when a parent is dying from cancer included: parental uncertainties surrounding if, when and how to tell the children that their parent was dying, the demands of managing everyday life, and preparing the children for the actual death of their parent. Many HSCPs felt ill-equipped to provide care to parents at end of life concerning their children. The results are discussed under two themes: (1) hurdles to overcome when providing psychological support to parents at end of life and (2) support needs of families for the challenging journey ahead.

Conclusions: There appears to be a disparity between HSCPs' awareness of the needs of families when a parent is dying and what is provided in practice. HSCPs can have a supportive role and help equip parents, as they prepare their children for the death of their parent. Appropriate training and guideline provision could promote this important aspect of end of life care into practice.

KEYWORDS
dying, end of life, health professionals, oncology, parental cancer, parental life-limiting illness, psychosocial support, parents, psycho-oncology, qualitative research

1 | BACKGROUND

Preparing dependent children (<18 years old, hereafter referred to as children) for the death of a parent is one of the greatest challenges faced by families, when a parent is dying from cancer.[1,2] This article refers to the term 'dying' when the death of a patient is anticipated within the next three months.[3] Often, parents feel ill-equipped to prepare their children for this end of life (EOL) experience.[4–6]

Where children are regularly informed of a parent's declining health at EOL and included in family communication, this enhances family functioning and trust between the child and parents.[4,7,8] Children prepared for the death of a parent adapt better long-term with improved psychosocial functioning,[9] compared to peers less

prepared for the death of a parent.[10,11] Often, parents feel they are protecting their children by not including them throughout the EOL experience.[6] There is a need to support parents to foster an environment of open and honest communication with the children, when a parent is dying from cancer.[6]

Parents have reported a need for guidance from health and social care professionals (HSCPs), as parents support their children throughout the cancer trajectory,[12] especially when the parent's health is declining and death is impending.[6,12,13] Despite parents' desire for guidance, the literature highlights this aspect of care is often not addressed as part of routine practice.[13] HSCPs have reported a lack of knowledge and confidence to provide emotional support for parents who are dying regarding their children, as well as highlighting environmental healthcare barriers such as time pressures.[13–15] These studies have predominately focused on oncology nurses,[13] whereas there are a variety of HSCPs who provide important clinical and non-clinical support when a parent is dying from cancer.[16] These include specialist (i.e. social workers [SWs], allied health professionals [AHPs], clinical nurse specialists [CNS']) and generalist (i.e. community and acute care nurses) HSCPs. While international studies demonstrate that 20%–78% of patients die in the acute setting,[17,18] global trends have reported an increase in patients dying in the community,[19] necessitating the need for this research to be inclusive of HSCPs across acute and community sectors.

Exploration of HSCPs' experience and perceptions of caring for families when a parent is dying from cancer will aid our understanding of how HSCPs working in clinical practice can be equipped to provide psychological care and support to parents concerning their children, when a parent is dying from cancer.

1.1 | Aims and objectives

The current study aims to explore HSCPs' experience and perceptions of providing care to parents concerning the children, when a parent is dying from cancer. The objectives of this study are to explore:

- HSCPs' experiences within routine clinical practice of providing care and support to parents concerning their children, when a parent is dying from cancer
- HSCPs' perceptions of the challenges experienced by families when a parent is dying from cancer
- HSCPs' perceptions of how parents can be best supported in relation to the children, when a parent is dying from cancer

2 | METHODS

A qualitative design using semi-structured interviews. The study is reported following the Consolidated Criteria for Reporting Qualitative Research guidelines.[20]

2.1 | Participants

Between March 2018 and August 2019, purposive and convenience sampling identified 32 HSCPs within one Trust in the United Kingdom. This method was considered most appropriate to ensure a diverse range of oncology and palliative care HSCPs across acute and community sectors were recruited to the study. Eligible participants were identified from a database and contacted by the fourth author [CJS] via email, and provided them with the participant information sheet, of which seven potential participants declined. Interested and willing professionals confirmed participation with the first author [JRH] who coordinated and facilitated the study.

2.2 | Data collection

Semi-structured interviews were carried out. A topic guide was developed and piloted, guided by the literature, alongside the research and expert group (Table 1). The expert group consisted of a palliative care SW and CNS, a family support worker and a bereaved parent and child (aged 14). Members of the expert group were identified from a healthcare Trust, a hospice service, and a family support service in Northern Ireland. The HSCPs within this expert group were recruited because of their vested interest and experience of delivering care to families at EOL. The topic guide was reviewed and iteratively modified as necessary, to enable follow-up with identified categories in subsequent interviews. Interviews were completed when no further categories were identified. Interviews took place within the healthcare setting, face-to-face, audio recorded and lasted between 20 and 50 min. The first author [JRH] who had no prior relationship with the HSCPs conducted the interviews.

2.3 | Data analysis

Audio recordings were transcribed verbatim and verified by the research team. Braun and Clarke's thematic analysis framework[21] was used to analyse the data. Initially, the first author [JRH] read and reread the transcripts to gain a sense of each participant's story. Following line-by-line scrutiny of the transcripts, the first author [JRH] coded the data using NVivo V12. Deployed as an inductive method, codes were developed by marking similar phrases or words in the participants' narratives. The first author collated the codes and identified where some of them merged into themes. To ensure rigour, credibility and trustworthiness, the codes and themes were independently analysed by three co-authors [EMcC, ERB, CJS]. Themes were verified and refined through discussion with all authors.

2.4 | Ethical considerations

HSCPs received oral and written information about the study and provided written consent. Participants were made aware of the right to

TABLE 1 Semi-structured topic guide used to guide the conduct of the study

Initial topic guide based on the literature, research aims and objectives and expert group
• Explore HSCPs' perceptions of the challenges experienced by families when a parent is dying from cancer
• Explore HSCPs' experiences of caring for parents when a parent is dying regarding the children
• Establish if providing care and support for parents who are dying regarding the children is part of routine practice
• How best could a HSCP help parents in routine care regarding the children when a parent is dying from cancer
Sample of additional topics following identification of initial categories
• Parental readiness in telling the children mum or dad is dying
• The role of the generalist versus specialist and acute versus community HSCPs
• Supportive clinical environments and emotional offloading

Abbreviation: HSCP, health and social care professional.

withdraw, and a distress protocol procedure was established to protect HSCPs. Data protection procedures were observed and assurances of confidentiality were given. Ethical approvals were obtained from Ulster University Filter Committee and South West—Cornwall and Plymouth Research Ethics Committee [REC:17/SW/0155].

3 | RESULTS

A varied sample of generalists *(n14)* and specialists *(n18)* from both the acute *(n17)* or community *(n15)* settings were recruited. HSCPs had at least 4 years experience working with cancer patients (*mAvg = 18years*, *range: 4–34 years*), with five who had formal training on caring for parents who are dying regarding the children. Sample characteristics are reported in Table 2.

Two overarching themes were identified: (1) hurdles to overcome when providing psychological support to parents at EOL and (2) support needs of families for the challenging journey ahead.

3.1 | Theme 1: Hurdles to overcome when providing psychological support to parents at EOL

HSCPs highlighted the importance of providing supportive care to parents at EOL regarding the children. However, the provision of this care was considered by most HSCPs as 'outside my remit'. Also, obstacles were perceived as barriers towards providing care to parents at EOL in routine care in relation to the children. These issues are further discussed under two sub-themes: (1) not my role and passing responsibility onto other HSCPs and (2) navigating an emotional obstacle course.

3.1.1 | Sub-theme 1.1: Not my role and passing responsibility onto other HSCPs

Most HSCPs described their role as providing physical care such as pain or symptom management, when a parent was dying from cancer.

TABLE 2 Characteristics of the 32 HSCPs recruited in the study

Variables	HSCPs *(n32)*
Acute specialists	
Palliative social worker	2
Palliative clinical nurse specialist	2
Palliative care consultant	3
Acute clinical nurse specialist	1
Oncology physiotherapist	1
Oncology clinical nurse specialist	3
Community specialists	
Community clinical nurse specialist	1
Oncology physiotherapist	1
Speech and language therapist	1
Occupational therapist	1
Palliative care educationalist	2
Acute generalists	
Acute care nurse	3
Chemotherapy nurse	2
Community generalists	
Community care nurse	9

Abbreviation: HSCP, health and social care professional.

Often, HSCPs working in the acute setting reported clinical interactions as too short and focused on the ill-parent's treatment needs. As a result, many HSCPs working within the acute setting perceived parental needs at EOL in relation to the children were 'picked up' by community teams. Despite this, within the community sector HSCPs often perceived this support was provided in the hospital setting, either at outpatient appointments or during inpatient admissions.

> *You know as a nurse you are restricted with time. Its like you come in, change the driver and leave. I would imagine that someone would have spoken to the parents about their kids when they got the bad news [HSCP 11; community generalist; community care nurse]*

Some specialist HSCPs working in outpatient clinics felt parents required time to process distressing information shared with them during their consultation. These HSCPs perceived engagement in conversations regarding the children could be *'too much'* for parents to handle in the same appointment, and perceived community care nurses were better placed to care for the needs of parents when mum or dad was dying from cancer. It was suggested by these HSCPs that the community care team would have insight to the particular needs of each family as a result of regular contact with the parents (and children) in the home.

> *Appointments here can be very distressing, particularly if it is bad news. But district nurses are rubbing shoulders with everybody who's coming into the house. They have more time to get to know the family and explore their needs [HSCP 03; acute specialist; palliative clinical nurse specialist]*

It was perceived by most HSCPs that healthcare disciplines such as counsellors and social care professionals, or family support workers at cancer charity organisations were better skilled to support families when a parent is dying from cancer.

> *I encouraged them [parents] to use the voluntary sector because they seem to be the right sort of people that can help [HSCP 08; acute specialist; oncology physiotherapist]*

Many of these HSCPs stated these disciplines would have the expertise to care for the needs of parents and their children at EOL. Some specialist HSCPs reported experiences of signposting parents to a family support service, if a parent suggested concern surrounding the impending death could have on the children. However, it was not clear if the support services were availed of or helpful for families, as HSCPs usually reported no follow-up with parents in relation to accessing these services. Alongside this, many HSCPs were unaware what the family support service actually offered.

3.1.2 | Sub-theme 1.2: Navigating an emotional obstacle course

Most of these HSCPs were parents who had dependent children and stated how they often *'put themselves in a patient's shoes'*, transferring how distressing the EOL experience is likely to be for parents. As a result, HSCPs talked about how emotionally challenging engagement in conversations with parents concerning their children could be and steered away from it.

> *Here was this thirty year old woman sitting in front of me who was probably in the last few weeks of life, and I was thinking about her little people at home. But I didn't talk about the kiddies then. I didn't want to upset her anymore, or myself at that time. I did tell her if she needed anything to get in touch [HSCP 02; acute specialist; palliative clinical nurse specialist]*

Furthermore, some suggested a display of their emotion could appear unprofessional and they had to *'keep it together'* to continue on to the next patient. Others suggested they felt unable to offload the emotional impact of providing care to parents at EOL, as they did not have access to clinical supervision and lacked support within clinical teams.

> *Emotionally I find patients with young teens more challenging because I find it hard to separate myself from the situation. I suppose I'm aware that's something that could make me emotional and I'm not there to cry. I've a job to get on with. [HSCP 13; community specialist; speech and language therapist]*

HSCPs stated they had a lack of confidence and, or rapport with parents they had just met to pursue in conversations regarding the children. Alongside this, HSCPs often reported a lack of knowledge on how best to provide parents with age-appropriate support for the children according to their developmental understanding. Also, HSCPs were concerned that discussing with parents how best to support their children may appear as interfering.

> *I wouldn't want to say do this and do that and then the child reacting bad to it. They [parent] would be coming back here saying why did that silly woman tell me to do that [HSCP 07; acute specialist; acute clinical nurse specialist]*

Some HSCPs reported there were a lack of opportunities to get the parent (either) alone to discuss what the children had been told and how to support them. On many occasions, both the clinical area and home lacked privacy. For example in the hospital only a curtain separating patients or in the family home whilst changing a syringe driver there were always people around. HSCPs perceived it would be inappropriate and insensitive to engage in emotive conversations with parents regarding the children when privacy was lacking or in the presence of others.

> *It would have been insensitive for me to ask the parent if the kids knew that she was going to die, and them [children] sitting in the next room. What if they didn't know and heard me [HSCP 20; community generalist; community care nurse]*

3.2 | Theme 2: Support needs of families for the challenging journey ahead

There was an awareness by some HSCPs of the need to empower parents to support the children, pre-bereavement. These HSCPs described how beneficial it would be if parents *'actively walked with the children'* through the EOL experience, involving them in decisions and care being provided. This could reduce the possibility of later adverse outcomes for the child's grief, such as guilt, mistrust and anger. These HSCPs reported experiences of responding to and caring for the needs of parents, when mum or dad was dying from cancer. Rather than the location of delivery of care (acute or community) or discipline of the HSCP, factors such as previous clinical and personal exposure to cancer and death appeared to impact on the level of supportive care provided.

> *I've been in the profession for over thirty years now, and over that time I've picked up some tips on what seemed to of worked well for some of these families. That exposure has shaped my confidence and practice [HSCP 17; acute specialist; oncology clinical nurse specialist]*

HSCPs highlighted perceptions of the challenges experienced by many families, and some reported how HSCPs could care for parents concerning their children in routine practice when mum or dad is dying from cancer. These are discussed under three sub-themes: (1) to tell or not to tell, that mum or dad is dying, (2) ongoing and changing needs and (3) preparing for the actual death.

3.2.1 | Sub-theme 2.1: To tell or not to tell, that mum or dad is dying

HSCPs reported that some parents thought it was best to tell the children mum or dad was dying, providing reasons such as the children would know *'something's wrong'*. Other parents were described as less forthcoming to disclose the reality of the situation with the children. These parents were perceived by HSCPs as protecting their children from pain and upset. Also, HSCPs talked about how some ill-parents were *'living and coping relatively well'* despite dying from cancer. Consequently, these parents were perceived as *'trying to keep things normal'* within the family with the hope that death was not so imminent, thus postponing sharing the reality of the situation with the children until there was an evident and rapid physical decline in the parent's condition. Other parents were described as focused on hope that the cancer could be cured, to which HSCPs viewed as parents denial surrounding the reality of the poor prognosis.

> *They were hopeful that the treatment was going to work. Their approach was to shield the children. I guess they didn't want to upset them [HSCP 22; community specialist; palliative care educationalist]*

Some HSCPs reported experiences where both parents had different ideas on how best to support the children. One example was where one parent (either) felt the children should be informed mum or dad was dying, and the other believed it was protecting the children from upset by not telling them. HSCPs perceived this to result in heightened levels of tension, worry and anger between the two parents. These HSCPs suggested it could be helpful if HSCPs encouraged both the ill and well-parent to tell the children that mum or dad was dying, as soon as possible, *'as they may know something is wrong and think it is their fault if not informed'*.

> *The daddy was quite dismissive of approaching the subject with the children. She [well-parent] felt like she couldn't go against him [ill-parent]. It was eating away at her [HSCP 15; community generalist; community care nurse]*

HSCPs stated that many parents were unsure how best to tell the children that mum or dad was going to die from cancer. HSCPs often suggested parents should have a *'natural conversation'* with the children, for example at the dinner table, and ask the children open questions to gauge understanding such as *'do you know what is going on?'* or *'are you worried about Mum or Dad?'*. HSCPs perceived it was good practice to encourage parents to avoid vague language with young children, such as *'Mummy is poorly'*. Rather, provide the children with small chunks of information such as, *'the doctors have tried their best to help Mummy, but she isn't going to get better'*, with regular updates surrounding the parent's treatment and declining health. It was reported some parents were concerned if the children would ask difficult questions such as *'when are you going to die?'*. A suggested response was *'we don't know exactly when, but we will take one day at a time'*.

3.2.2 | Sub-theme 2.2: Ongoing and changing needs

HSCPs perceived some parents were 'family-managing' the dying period with the children and had relatively clear plans to navigate the parental role throughout the EOL experience. It was reported these parents appeared to be openly communicating with their children about the reality of the parent's declining health. Other parents were suggested to have reached out themselves to cancer charity organisations for support in relation to preparing the children for the actual death of the parent, or engagement in pre-bereavement activities such as writing letters for the child's future or 'memory boxes'.

However, HSCPs did describe how the unfolding EOL experience was demanding for many well- and ill-parents. Often, well-parents were perceived as juggling different roles when mum or dad was dying, such as taking a lead in parenting, caring for the partner and responsibility (sometimes sole) for being the primary earner. It was suggested by HSCPs that increased parental responsibilities or managing the home was *'alien'* to some well-parents, as this was not the typical role the mum or dad played in

the family before the poor prognosis. HSCPs perceived some well-parents were overwhelmed in managing day to day parenting tasks when mum or dad was dying.

> *The chap had his work cut out for him. He was coming up and seeing his wife and on top of that running round looking after two boys and managing the farm. He seemed exhausted [HSCP 09; acute generalist; acute care nurse]*

It was reported some ill-parents appeared to struggle to do everyday parenting activities as a result of declining health, to include taking the children to school or cooking meals for the family. Some community care nurses and AHPs outlined examples of helping the ill-parent to practically carry out the parenting role at EOL, such as sourcing volunteers to help with grocery shopping or driving to appointments, and obtaining physical aids so the parent could attend the child's sports day.

> *She went off her feet but was adamant about getting to the daughter's sport's day. So we were able to facilitate getting a wheelchair and taxi with wheelchair access, so she could be part of that [HSCP 16; community generalist; community care nurse]*

Also, HSCPs reported how some well-parents were unable to maintain usual employment hours, as a result of balancing different parenting and caregiving roles when mum or dad was dying. HSCPs described some of these parents as having money worries to *'getting by'*, as a result of a reduced household income. It was perceived helpful to families when the HSCP informed parents of the sources of financial benefits the family were entitled to.

> *He [ill-parent] started a new treatment which made him quite sick and spent a good few weeks as an inpatient. She [well-parent] stopped work at this stage to be with him, but the money was getting tight [HSCP 17; acute specialist; oncology clinical nurse specialist]*

3.2.3 | Sub-theme 2.3: Preparing for the actual death

HSCPs perceived parents were often uncertain how to navigate the active dying stage with the children. This included sharing the news that mum or dad was moving to a hospice, or may not return home from hospital, or was coming home from hospital to die. Also, parents were often perceived anxious if the children could be present when mum or dad was actively dying. In situations where the dying parent was perceived not to be in *'distress'*, some HSCPs reported providing advice to parents on offering the children the choice to be present when their mum or dad was actively dying, as being present could help the child's understanding of how the parent died.

> *Her husband was dying and she was just looking at me for answers or for something to help along in her thoughts. She didn't know what to do about her son [HSCP 01; acute specialist; palliative social worker]*

It was suggested that some parents themselves were unaware of what the death process would look like physiologically, as they had never seen a death before. As a result, these families were perceived as unsure how best to prepare the children for the actual death of a parent. One acute care nurse suggested it could be helpful if HSCPs informed parents of the process of what may happen during the active dying phase such as colour changing, excess secretions, and lack of consciousness, so the well-parent is equipped to prepare the children when mum or dad is actively dying.

4 | DISCUSSION

Findings highlighted HSCPs' experience and perceptions of the challenges and complexities encountered by many families when a parent is dying from cancer. Challenges reported included parents' uncertainly to tell or not to tell the children that mum or dad is going to die, challenges surrounding juggling of parental responsibilities when a parent is dying, and preparing the children for the actual death. However, many HSCPs reported a lack of confidence and felt ill-equipped to provide care to parents regarding their children when mum or dad was dying from cancer. These perceptions have been echoed in studies with oncology nurses by Arber and Odelius,[22] Dencker et al.[23] and Turner et al.[24] However many HSCPs in this study, whether in the acute or community setting, felt it was not their role to provide advice and guidance to parents at EOL regarding their children.

Providing psychological care to parents in relation to their children when a parent is dying from cancer was highlighted as a highly emotional activity for HSCPs. It is possible HSCPs in this study did not feel comfortable engaging in these emotive conversations at EOL for a fear of causing parents[25] or themselves[26,27] further distress. In addition, HSCPs are unsure if it is their role, and if so, how and when is it appropriate to open up conversations with parents who are dying regarding their children, as parents often need time to process this distressing information.[28] Multiple other factors and complex family dynamics can influence and inhibit the provision of advice to parents about what to tell their children when mum or dad is dying with cancer from HSCPs, such as knowledge of a child's developmental stage and/or learning needs,[24] background family factors relating to divorce or separation,[29] and their previous or vicarious experiences. Other possible explanations as to why this aspect of care is often lacking in clinical practice includes: a desire to avoid an emotional attachment with a dying patient,[30] HSCPs' focus of providing physical rather psychological care,[31] and shifting responsibility of the role to other HSCPs.[32]

Engaging in conversations with parents at EOL concerning their children appears to be difficult for HSCPs to have.[13] Alongside this,

obstacles may act as barriers towards the provision of supportive care to parents at EOL concerning their children. For example some parents may not feel emotionally ready to tell their children mum or dad is going to die, some parents may feel they have 'more time' and do not feel the need to prepare their children for an uncertain future, and some parents may be adamant that protecting their children is not to tell them the reality of the situation.[6,13] There is a need for parents to understand that some necessary preparation is helpful and protective for their children surrounding the inevitable death of their mum or dad.[9,33] HSCPs are ideally placed between acute and community sectors and 'outside' the emotional tension in the family to encourage this forward planning, and navigate parents through the dying period when there are heightened family needs.[6] There is a requirement for training to equip HSCPs with the knowledge and confidence to provide these challenging aspects of care, and to know when it may be appropriate and where to refer parents onto specialist services.

4.1 | Clinical implications

To help facilitate adjustment for their child's future, parents should be encouraged to prepare children for their parent's death as early as possible, as the ill-parent's health could deteriorate quickly and the parents may be less able to support the children at that time. Therefore, HSCPs should equip parents by encouraging and supporting them to consider and plan how best to tell their children that mum or dad is going to die from cancer, when the parent is presented with the poor prognosis. Preparing and supporting the children earlier may reduce the stress and demands often experienced by the well-parent when the ill-parent is actively dying. Encouraging open communication alongside a child's sense of inclusion within the family are factors that can mitigate adverse effects into adult life.[6,9,34] It may be helpful if HSCPs equipped parents with age-appropriate language as they prepare to tell their children that mum or dad is going to die (see section 'to tell or not to tell, that mum or dad is dying' for detail), and when the ill-parent is actively dying (see section preparing for the actual death for detail).

It would also be pertinent for HSCPs who are caring for parents at EOL to identify, and help them with ongoing needs at EOL such as obtaining practical support and, or financial support. Guidelines and training may promote HSCPs' awareness of their pivotal role, and to increase their confidence to provide supportive care to parents concerning their children, when mum or dad is dying from cancer.[13,35] Provision of this training could be incorporated as a dedicated component within Advanced Communication Skills Programmes,[36] equipping HSCPs with the necessary language to support parents to have age-appropriate conversations with children when their parent is going to die, and preparing parents for difficult questions.

To protect HSCPs against professional and emotional burnout and enhance the provision of family-centred cancer care, it would be pertinent that HSCPs are equipped and trained to deliver this aspect of care. This includes regular routine clinical supervision sessions for opportunities to discuss professional challenges of caring for parents in relation to the children when a parent is dying from cancer. Also, evaluation of healthcare structures and services could inform the development of interventions to target constraints such as high workloads, time pressures and lack of privacy. This could enhance HSCPs' provision of helping parents to support the children pre-bereavement, which could facilitate better coping for children in the future.[9,34]

4.2 | Study limitations

Despite a varied sample of acute, community, specialist and generalist HSCPs, findings are limited to HSCPs working within one Trust in the United Kingdom. Findings are representative of healthcare Trusts in Northern Ireland which do not have a dedicated family support worker. It is possible the presence of a family support worker in other healthcare settings may have an impact on HSCPs' provision of supportive care to parents at EOL concerning their children. It is possible HSCPs current role of caring for parents in other settings may vary, such as ethnically diverse cultures. While the findings may be applicable to other life-limiting conditions, the study focused on HSCPs' experience and perceptions of caring for parents dying from cancer.

5 | CONCLUSION

Through the lens of HSCPs, this study provided insight to the complexity of some of the challenges faced by many families when a parent is dying from cancer. HSCPs can have an important role to equip parents in routine care, to support their children when a mum or dad is dying from cancer. However, there appears to be a disparity between HSCPs awareness of the needs of parents at EOL concerning their children, and the provision of supportive care in routine practice. There is a need for HSCPs to recognise their pivotal role in providing support to parents concerning their children when a parent is dying from cancer, and empower and equip HSCPs in the provision of caring for the needs of this population. Policy guidelines should also be developed to incorporate this aspect of care into routine clinical practice.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available at the Ulster University Repository and available on request from the first author. The data are not publicly available due to privacy and ethical restrictions. The study passed ethical committee review [REC:17/SW/0155].

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4.5 The role of funeral directors in providing pastoral care to parents concerning the children in the immediate bereavement period, when a parent of dependent children has died from cancer (Paper 4)

This section reports the findings of the funeral directors included in the study. Overall, 23 funeral directors between private and public limited companies across rural and urban settings within Northern Ireland were recruited to this study; to explore their experience and perceptions of providing a service to families when a parent of dependent children has died from cancer. Findings highlight the emotionally charged and painful situation for bereaved parents in the immediate bereavement period, following the death of a parent of dependent children, and the supportive role funeral directors can have in guiding parents through this distressing period. Results are discussed under three broad themes: (1) funeral directors' perceptions of challenges experienced by families surrounding the time of parental death, (2) funeral directors' perceived role in navigating the family through the immediate bereavement period and (3) societal shifts influencing the immediate bereavement period when a parent dies from cancer. This paper was published in Death Studies.

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Immediate bereavement experiences when a parent of dependent children has died of cancer: Funeral directors' perspectives

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ABSTRACT

When a parent of dependent children dies, families are often unsure if and how children could be part of the immediate bereavement period. Children excluded can be more susceptive to negative outcomes. In-depth interviews explored funeral directors' ($N = 23$) experiences of providing a service to families in the immediate bereavement period, when a parent dies from cancer. Findings highlighted funeral directors can have an important role in guiding families through the distressing immediate bereavement period. Recommendations are discussed surrounding a pastoral role of the funeral director in the immediate bereavement period.

Although death is commonly associated with old age, there is an increasing number of dying younger adults with dependent children (aged under 18 years; Parsons, 2011). Where the death of a parent with dependent children is expected from cancer, ideally the reality of the parent's declining health should be openly discussed within the family (Fearnley & Boland, 2019; Hanna et al., 2019; Sheehan & Draucker, 2011). The level of open communication varies between families, and children are often ill-prepared or unaware their parent is going to die from cancer (Beale et al., 2004).

Despite varying levels of preparations for children when a parent is dying from cancer, families, particularly the bereaved parent, encounter new challenges when the ill-parent has just died (McClatchey, 2018). The bereaved parent, or other significant adult in the child's life, is then confronted with the highly emotive and challenging task of supporting the children at this distressing time of death (Sheehan et al., 2019) and the immediate bereavement period (i.e. the time from the death to the funeral) that follows.

In recent years, Ireland has become increasingly secular and ideologically more diverse (O'Flaherty et al., 2018). Nonetheless, it remains one of the most Christian countries in western Europe, where four out of five Irish people identify themselves as Christian, with 50% of whom identifying as nonpracticing (Pew Research Center, 2018). However, when families encounter the death of their loved one, customary rituals often prevail (Walter, 1994). In Ireland, traditionally the home becomes "the wake house" during the immediate bereavement period where friends and family alike gather, usually sharing memories and stories about the deceased (McCarthy, 2016). Following the death, the funeral director brings the deceased body into their care, which is prepared for the coffin at the funeral director's place of work. Usually, the body is returned to the home in the coffin by the funeral director and remains there until the night before or day of the funeral. However, in recent years there has been a shift toward the body remaining at the funeral parlor (McCarthy, 2016). It has become a practice in Ireland for the funeral of an individual to be around the third day after death.

Newly bereaved parents are often unsure of how to navigate the immediate bereavement period with their dependent children (Schonfeld et al., 2016). Despite a child's desire to be part of the decision-making and rituals that follow (Weller et al., 1988), families often feel it is protective to exclude children from the planning and delivery of their parent's funeral (Silverman, 2013). Studies have reported that children excluded during the immediate bereavement period are more susceptive to feelings of regret, anger, hurt, and frustration than those children included (Holland, 2004; Paul, 2013).

Researchers from the Harvard Medical School Child Bereavement Study reported the importance of

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children maintaining a relationship with their parent that has died (Silverman et al., 1992; Silverman & Nickman, 1996; Silverman & Worden, 1992); these relationships are often referred to as "continuing bonds" (Karydi, 2018). Factors that promote continuing bonds between a child and the recently deceased parent during the immediate bereavement period include listening to and sharing of stories regarding the dead parent during the wake (Haine et al., 2008), writing poems or letters and placing these inside the coffin with the parent (Faro, 2018; Holland, 2004; Mahon, 2009; Søfting et al., 2016), and choosing the flowers or music for the funeral service (Holland, 2004; Mahon, 2009; Søfting et al., 2016). Other studies have reported involving children in the immediate bereavement period helps them understand the finality of death (Christ, 2000) and feel valued as a family member (Søfting et al., 2016; Worden, 1996), which can help facilitate better adjustment and coping into adulthood (Christ, 2000; Faro, 2018; Fristad et al., 2001; Holland, 2004; Saldinger et al., 2004; Silverman & Worden, 1992; Søfting et al., 2016; Weller et al., 1988; Worden, 1996). These studies highlight a need for families to be reassured about and encouraged to involve the children throughout the immediate bereavement period.

Funeral directors are centrally involved in organizing and conducting nearly all funerals in Ireland and work closely alongside the bereaved family during the immediate bereavement period (Holloway et al., 2013). Also, funeral directors are usually the only professional consistently present within the family home throughout the 3-day period. Elsewhere, funeral directors have been identified as having an important role. In the United States, they might provide families with direction in preparing and involving the children during the immediate bereavement period (Mahon, 2009). In Australia, funeral directors have been identified as one of the most common forms of bereavement support to families (Aoun et al., 2018). However, in some countries (including Northern Ireland), funeral directing is not a regulated profession and lacks an accountability structure regarding standards of service provision (Valentine et al., 2013). Although Howarth (1996) noted funeral directors have a role in advising bereaved adults on how to arrange and prepare for the funeral of a loved one, it is unclear if funeral directors perceive it is their role to extend this care and support to families in relation to the children, when a parent of dependent children has died. Exploration of funeral directors' experiences of providing a service to bereaved families may offer insight to the challenges faced by newly bereaved parents, as they manage the distressing immediate bereavement period with their dependent children. Also, it will aid our understanding of the role a funeral director can have in supporting a bereaved family through the emotional immediate bereavement period, when a parent of dependent children has died from cancer.

The current study aims to explore funeral directors' experience and perceptions of providing a service to families when a parent of dependent children has died from cancer. The objectives are to explore funeral directors' experiences of providing care and support to families when a parent of dependent children has died from cancer, funeral directors' perceptions of the challenges encountered by the bereaved parent when a parent of dependent children has died from cancer, and funeral directors' perceptions of good practice for families when a parent of dependent children has died from cancer.

Methods

Participants

Initially, we used convenience sampling to recruit funeral directors from private limited companies, where it was suggested that the service provided by funeral directors varied between private and public limited companies. Private limited companies are typically small businesses with funeral directors comprising family members. Public limited companies are typically practices or franchises made up of multiple funeral directors. Purposive sampling was deployed to ensure representations of funeral directors from private and public limited companies within rural and urban communities.

Eligible participants were contacted by the first author via telephone and provided with oral information regarding the study. A total of 15 potential participants declined the invitation. Explanations for nonparticipation included a lack of availability and perceptions of having a lack of professional experience to meaningfully take part. Twenty-three funeral directors

Table 1. Participant characteristics.

Variables	*n*	%
Gender		
Male	19	83
Female	4	17
Company type and location		
Private limited company, rural	10	43
Private limited company, urban	5	22
Public limited company, rural	3	13
Public limited company, urban	5	22
Obtained the National Association of Funeral Directing diploma	14	61

from Northern Ireland participated. Participants were informed the study would explore their professional experience and involvement in working with families, when a parent of dependent children has died from cancer. Participants recruited consisted of funeral directors from private limited companies ($n = 15$) and public limited companies ($n = 8$), between rural ($n = 13$) and urban ($n = 10$) communities. All participants had at least two years' experience as a funeral director (mean = 24 years, range = 2–54 years). Sample characteristics can be found in Table 1.

Data collection

Data were collected between November 2018 and March 2019 using semi-structured, in-depth interviews. This method is considered most appropriate for providing rich data surrounding an individual's experience (DiCicco-Bloom & Crabtree, 2006). A topic guide was developed, informed by the literature and the study's aims. Open-ended questions included: "can you tell me about your experience of working alongside families when a parent of dependent children has died from cancer?," "what do you see as challenging for families in the immediate bereavement period when a parent of dependent children has died from cancer?," and "what has been your professional role when providing a service to families in the immediate bereavement period when a parent of dependent children has died from cancer?" Follow-up probes were used to gather more detail on funeral directors' experiences and perceptions, such as "what happened then" and "can you tell me more about that." Additional topics included: a family's struggle to sharing information with young children during the immediate bereavement period and generational shifts toward the immediate bereavement period when a young parent has died from cancer. Interviews were conducted face-to-face by the first author and some were co-facilitated with wither the second or third author. The authors had no prior relationships with the participants. Interviews were audio-recorded and lasted between 30 and 50 min at each participant's place of work. Audio-recordings were transcribed verbatim by the first author.

Data analysis

Braun and Clarke's (2006) thematic analysis framework was used to interpret the data. Deployed as an inductive method, the process of identifying themes in the study was derived from the data (Maguire & Delahunt, 2017). Initially, the first author read and reread the transcripts to gain a sense of each participant's story (Braun et al., 2019). Following line by line scrutiny of the transcripts, the first author coded the data using NVivo V12. As an inductive process, open coding was used and codes were developed by marking similar phrases or words in the participants' narratives. To enhance validity, the codes were independently analyzed and discussed with the third author, which resulted in two codes being renamed. Following the coding of the data, the first author collated the codes and identified where some of them merged into themes. Due to the overlap between the themes, these were reviewed and discussed with the third author. To ensure rigor, credibility, and trustworthiness, codes and themes were independently analyzed by the second coauthor. Themes were verified and refined through a critical dialogue with all authors.

Ethical considerations

Participants received oral and written information about the study and provided written informed consent. Assurances of confidentiality were given and data protection procedures were observed to protect participants. Ethical approvals were obtained at institutional and national levels [REC:17/SW/0155].

Results

Overall, three themes were identified from the data: funeral directors' perceptions of challenges experienced by families surrounding the time of parental death, funeral directors' perceived role in navigating the family through the immediate bereavement period, and societal shifts influencing the immediate bereavement period when a parent dies from cancer.

Funeral directors' perceptions of challenges experienced by families surrounding the time of parental death

It was reported that families (particularly the bereaved parent) varied in the ability to cope and navigate the immediate bereavement period with their children. Funeral directors stated some families had invested time before the death, where the children had been informed and regularly updated on the changing nature of their parent's declining health. On occasions, the children had been part of conversations surrounding the forthcoming death of their mum or dad and funeral arrangements. Other families were

reported by funeral directors as less prepared for the parent's death and were uncertain how to self-manage the immediate bereavement period with the children. The data highlighted uncertainties faced by many families, as observed by funeral directors in the immediate bereavement period when a parent has died from cancer.

Before face-to-face contact between the funeral director and the family, it was reported some bereaved parents had struggled with finding the appropriate language to tell young children (up to 12 years old) that their mum or dad had died. Many funeral directors reported that parents told young children ideas such as their parent going to heaven or becoming an angel or a star. Funeral directors stated euphemisms such as appeared to be ambiguous for some young children and perceived it good practice for parents to use clear language, ensuring the child understood the permanency of death.

> Time and time again I hear children saying, "my mummy is an angel" and while that's all lovely and nice, the child then thinks mummy will come back and live with them as this angel. Kids need to know that death is irreversible. [Funeral director 15]

Funeral directors often described the immediate bereavement period as chaotic for the newly bereaved family, as it was usually their first experience of an immediate family member's death. Consequently, the family was often unsure of the logistics surrounding the immediate bereavement period. In addition to the practicalities, one of the greatest challenges perceived by funeral directors adding to newly bereaved parents heightened distress was how best to support the needs of the children.

> I got to the home and everybody was in a state. I think it is fair to say that the adults generally were a bit lost and didn't know what to do with the kids. [Funeral director 2]

The funeral director usually met with the family shortly after the death to discuss arrangements. This provided an opportunity (and in some cases the only time these conversations took place) to make preparations for the immediate bereavement period, including the funeral. Bereaved parents were often described by funeral directors as uncertain as to whether the children should be present when funeral arrangements were being made. While some parents were reported to have already decided how their children would be involved, others were reported to have sought reassurance and direction from the funeral director concerning their child's participation on key aspects of the immediate bereavement period. This included the bereaved parent's uncertainty surrounding their child's involvement in the home during the wake, or if the young children should attend the church, crematorium, or graveyard on the day of the funeral. Also, funeral directors perceived many bereaved parents were unsure if bringing the body home would expose the children to heightened levels of distress.

> It's usually us (funeral directors) asking the questions about what a family want for a funeral, but when I've been sitting in the home of a young family, they are the ones asking us the questions. They (the bereaved parent) are beside themselves. The kids are the forefront of their mind and they are searching for answers as to how they are going to get through the next few days with the kids. They're looking to us for that guidance. [Funeral director 17]

While many families impacted by divorce or separation were reported to "come together in their grief," some funeral directors described heightened levels of conflict was evident amongst others. Factors perceived to contribute toward tension and conflict included a previously absent parent "taking over" parenting or the presence of a new partner (step-parents). Funeral directors perceived these family dynamics often led to anger and resentment from the children (typically teenagers) and other family members. In such situations, some funeral directors perceived their role was to facilitate dialogue within the family to "calm" the situation and provide the whole family (children and adults) with ownership in the planning and delivery of the funeral. Other funeral directors were not involved in this depth and focused on planning the funeral with the key family members. These funeral directors perceived intervening would have been inappropriate as it was "a family matter." Funeral directors perceived "family functioning" was promoted when funeral plans were discussed with the dying parent before the death occurred.

> Like many families, they had their own baggage. I didn't want to find myself stuck in the middle of it. At the end of the day, I was there to get the funeral planned. I wasn't there to be a mediator for the family. That's something they had to work out amongst themselves. [Funeral director 25]

Death was described as difficult for any family. However, funeral directors described observing a more emotionally charged and "raw" situation when a parent of dependent children has died compared to that of an older person. For instance, funeral directors stated a greater degree of personal distress when working with families when a parent of dependent children has died. Some of these funeral directors

were parents or grandparents of dependent children and stated how they often thought "what if this happened to my family," transferring the pain experienced by newly bereaved young families. Also, funeral directors reported feeling upset at the thought of a parent missing out on their children "growing-up" and important milestones in life. Often, funeral directors described a lack of opportunity to offload this emotional impact of the funeral director role.

> You can't help but put yourself in their shoes and think what if I or my husband had to go through this pain. So many times, I've left the home of these young families and came back to the office just bawling my eyes out. They are just horrendous situations. [Funeral director 14]

Funeral directors' perceived role in navigating the family through the immediate bereavement period

There were a wide variety and range of professional input from the funeral director but this did not appear to differ between the funeral director role in relation to the funeral director's gender, company type (private or public limited company), or location (rural or urban). Some funeral directors described their role as providing a service in coordinating the planning and logistics of a funeral. Often, these funeral directors did not perceive it was their professional role to help families navigate the immediate bereavement period with dependent children. Factors contributing toward these perceptions included fear of interfering which may cause further distress to a bereaved family's situation and feeling they (the funeral director) were not in a position to influence parents on how to navigate the immediate bereavement period with their children. Also, some funeral directors described the funeral director role as demanding, often dictated by imminent timelines. For example, decisions regarding a funeral are often made within a period of 2 hr so newspaper notices can be submitted on-time, or funeral directors have other commitments such as another funeral to coordinate or a second job.

> I could get a call out at 9 o'clock in the morning and have another funeral to conduct at noon. That gives me three hours to get the planning done and be ready for the next funeral. There's a limit on what we can to do. [Funeral director 19]

Other funeral directors perceived the funeral director role more widely in that it included providing families with appropriate reassurance and direction as the family navigated through an unfamiliar and highly emotive experience. Often as parents themselves, funeral directors wanted to help these parents as best as they could at an emotionally difficult time. Also, funeral directors considered this was an integral aspect of high-quality service that funeral directors should provide, while simultaneously promoting company reputation and maintaining competitive in the business. Funeral director input was predominately based on previous experience in the professional role as a funeral director; they stated they did not have specific education or training on how to support families with dependent children during the immediate bereavement period. The role of the funeral director during the immediate bereavement period is further discussed under two sub-themes: preparation to view the parent in the coffin and involving children at the funeral.

Preparation to view the parent in the coffin

Most funeral directors stated it was good practice for bereaved parents to encourage children to see their mum or dad in the coffin. Based on previous experience, many funeral directors perceived it would contribute toward the child's understanding and acceptance of the death. However, funeral directors often stated bereaved parents sought advice to prepare the children (usually young children) for viewing their parents in the coffin. Some funeral directors suggested they advised the parent to provide children with factual details of the process of what they will see. For example, in most cases a wooden box known as a coffin will be brought home in a "long black special car" called a hearse, explaining what their mum or dad will be wearing, and how the body will look, feel (cold, firm, perhaps jaundiced, or blue lips), and be positioned. This detailed preparation was suggested to facilitate reassurance to the child's understanding that the person in the coffin is their parent.

> It's just about being truthful and saying this is how they'll (the deceased parent) look. You're not telling them any lies and therefore they'll (the children) be prepared for what they are going to see. [Funeral director 4]

A small number of funeral directors perceived it was their role to be present when families were having this conversation with young children, so they (the funeral director) could answer any difficult questions the children may pose. Other funeral directors simply discussed the practicalities of the immediate bereavement period and did not participate in this depth of conversation with families.

In preparation for viewing, some funeral directors felt they had a key role in ensuring the parent would look, as much as possible, as to how the child would remember them. For instance, some funeral directors

would ask for a photograph of the parent that has died, or ask the bereaved parent to view the body before the children, to take small details into consideration such as the parent's hair or wearing glasses. For young children, funeral directors ensured there were chairs or stools in the room with soft furnishings such as toys. This was to allow the children to have a comprehensive view of their mum or dad, representing how they typically would see their parents in a sensitive environment.

> We want it to be a good experience particularly where young children are present. We don't want children to be walking into this cold room. We always make sure there's toys or teddies lying around. It makes it that bit less terrifying. [Funeral director 12]

To facilitate coping, some funeral directors suggested it appeared helpful for children (typically, young children) to add something in the coffin with their parents. This was suggested by funeral directors to provide children with a purpose in the viewing and promote the feelings of comfort and connection. Examples outlined by funeral directors included handmade cards, photographs, drawings, or a teddy; "To me, that's a real big benefit. They're sending this message or picture away with their mummy or daddy and probably helps them in their grief" [Funeral director 5].

Involving children in the funeral

As families prepared for the funeral, many funeral directors reported bereaved parents were often uncertain of how best to involve their children. Funeral directors stated children (especially young children) are often not included when funeral plans are being discussed between the funeral director and the family. Many funeral directors perceived children should be involved in the planning of the funeral, as a means of providing them with ownership and belonging. However, only some funeral directors reported actively offering this suggestion or encouraging the bereaved parent to include the children in the planning and delivery of the funeral. From experiences of including children, funeral directors stated they could see the benefit for children choosing flowers and music for the funeral service, or the outfit the deceased parent was wearing in the coffin. This was reported by funeral directors to help the children keep connected to the dead parent and part of "saying goodbye."

> Last week, I was walking down the street and this chap came up to me. I hadn't a clue who he was; we meet so many people in the job. Anyhow, he told me I was the funeral director when his mum died some 10 years ago and he thanked me for all I had done during the time of the funeral and how that was helpful for him. That gives me comfort in what I'm suggesting to these families is a good thing. [Funeral director 16]

Many funeral directors reported that children often have not attended a funeral before and have little understanding regarding "how it will be." To prepare children for their parent's funeral, some funeral directors reported it was useful for children (usually young children) to view the funeral home, crematorium, or graveyard in advance and talk through the service. Funeral directors suggested this helped provide children with an understanding of what would happen on the day of the funeral, endeavoring to make it less frightening. It was reported these advanced preparations were helpful to manage any worries or concerns children had, as it provided them the opportunity to ask questions regarding the funeral venue or structure to the bereaved parent or funeral director.

> Just like any inquisitive child, she came and it was "what's this" and "what's that used for?" and to the best of my ability I was able to explain that all to her. But it was more about normalizing the funeral home and preparing her for what was to come. [Funeral director 10]

It appeared that some funeral directors were focused on coordinating the practicalities surrounding the day of the funeral. Other funeral directors highlighted experiences of reassuring and informing families that children can be meaningfully involved in the delivery of their mum or dad's funeral. This has included children being involved during handshakes or hugs to gain comfort from the family and friends who came to express support and sympathy at the funeral and giving offertory religious gifts or symbols during the service. Other examples provided specifically for young children included placing their hand on the coffin as it was being carried and throwing a flower into the grave. Other suggestions offered by funeral directors surrounding how teenagers could be involved in delivery of the funeral included giving personal readings or poems as a tribute to the parent during the funeral service.

> You know, I had plenty of cases where the family would say, "what do we do with the kids on the day?" and I would say, "ask them if they want to be involved." You know, maybe the "wee-ones" might like to take a flower out of the spray and throw it into the grave. [Funeral director 19]

Funeral directors reported attendance at funerals vary as a result of factors such as how well the individual was known or the size of the family. However, funeral directors often identified funerals of younger parents as largely attended. Some funeral directors

suggested it to be good practice to nominate an adult such as an aunt, uncle, or close friend to each individual young child in the family on the day of the funeral. This was suggested as a means of reassurance to the bereaved parent that their young children would be looked after, particularly in cases of distress or where the children may be separated from the parent.

> I'd usually advise the family to have a plan B. You know, if the child got upset during the service then aunty Joan can take them out as opposed to the whole family having to go [Funeral director 21]

Societal shifts influencing the immediate bereavement period when a parent dies from cancer

As generations have evolved, many funeral directors identified societal shifts as influencing families' approach to the immediate bereavement period. This has included an increase in children attending the funeral. Although still predominately traditional within church and religious environments, funeral directors have witnessed a greater openness for more bespoke requirements for younger families in Northern Ireland. This has included neutral venues for funeral services, such as sports clubs and community centers and cremation rather than burial, and a rise in humanist-led services as a result of less connection to traditional church religion amongst the younger generation.

> I'm certainly mindful that times are changing and so are people's expectations. You can't just assume the funeral is going to be in the local chapel. I mean, the last funeral that I conducted of a young parent was held in the local football club. [Funeral director 07]

Funeral directors reported that society as a whole appeared to be increasingly regarding the funeral as a celebration of the person's life to achieve an uplifting experience. Funeral directors stated that families, especially when the person who has died is younger, are more inclined to personalize the funeral according to traits and values of the person who died. Examples reported included wearing jerseys of the decease's favorite sporting team, or having the coffin sprayed in their favorite color or wrapped in photographs.

> Younger families realize they don't have to go humdrum and it can be a celebration of life and not this depressing dirge. They are more open to newer ideas and ways of thinking. [Funeral director 17]

Discussion

Findings highlighted funeral directors' perceptions of the challenges experienced by many families in the immediate bereavement period when a parent of dependent children has died from cancer. Identified challenges included: a bereaved parent's struggle to tell the children their mum or dad has died, a family's uncertainty toward including the children in the planning and delivery of the funeral, and preparing children to view their parent in the coffin.

The care and support provided to young families in the immediate bereavement period by funeral directors varied. Some funeral directors described their role as focused on coordinating the logistics of a funeral. It is possible that some of the funeral directors in this study did not want to engage in emotive conversations with bereaved parents concerning their dependent children so soon after the death for a fear of causing further distress to the parent's grief (Hayslip et al., 2007). Transference of the emotion and pain experienced by the young newly bereaved family is perhaps why some funeral directors felt unable to provide meaningful support to families in the immediate bereavement period. Other explanations may include a lack of clear guidelines and training for funeral directors on how to provide care and support to families in the immediate bereavement period, or perceptions the needs of families following the death of a parent are addressed by other professionals such as clergy members (Fowler, 2004; French, 1985). Involvement of children in the immediate bereavement period is a relatively new concept in Western cultures; therefore, it is possible that some funeral directors were unaware of the challenges faced by newly bereaved parents (Doka, 2000; Dyregrov & Kristensen, 2020). Also, some funeral directors may have been motivated by profit, rather than providing a pastoral role to families in the immediate bereavement period when a parent of dependent children has died (Bailey, 2010; Bradbury, 1999; Howarth, 1996).

Other funeral directors felt that helping families navigate the immediate bereavement period with the children was an instrumental aspect of their role, echoing Mahon's (2009) findings. Usually, this was a result of funeral directors' desire to help parents navigate a painful experience with their children and alleviate part of the suffering experienced by the newly bereaved family. However, it also appeared the depth of care and support provided by a funeral director was impacted by their (the individual funeral director) desire to promote company reputation and remain competitive in the funeral directing industry. It may be argued that individuals now "shop around" when choosing the service of a funeral director, rather than selecting the service most convenient to them

(Parsons, 2003; Woodthorpe, 2017; Woodthorpe & Rumble, 2016). Funeral directors stated many young bereaved families have little experience of organizing (or even attending) a funeral. Thus, families are unable to choose the service of a funeral director based on previous satisfactory experience (Hopwood, 1996; Parsons, 2003), but decisions based on reported customer satisfaction of others, centered on their "good reputation." Furthermore, although funeral directors provide a needed service in a Western culture such as Northern Ireland (Howarth, 1996), custom is not guaranteed in a competitive and growing market (Parsons & Parsons, 2018; van der Laan & Moerman, 2017). This may allude to a funeral director's desire to "go that extra mile" when caring for bereaved families in the immediate bereavement period, when a parent of dependent children has died.

Funeral directors can have an instrumental role in providing care and support for a family during the immediate bereavement period, specifically in relation to dependent children. This includes: encouraging a family that children can be meaningfully involved in the preparations and throughout the funeral period, reassuring a family that children can view their mum or dad in the coffin, and providing a bereaved parent with clear language as they prepare the children for these events. If this pastoral care were incorporated as part of the funeral directing role, it could empower a bereaved parent's provision of supporting their children in the immediate bereavement period, which could help mediate negative coping into adulthood (Christ, 2000; Fristad et al., 2001; Holland, 2004; Silverman & Worden, 1992; Søfting et al., 2016; Worden, 1996). Further research is needed from bereaved parents and children to have a better understanding of their needs during the immediate bereavement period, as funeral directors' perceptions of familial challenges during this period bore from personal experience alone, rather than evidence-based guidelines or educational intervention.

It was perceived that advanced planning of the funeral aided family functioning when the parent had died. Other literature has reported that knowledge of a loved one's wishes facilitated ease for the family, when making funeral arrangements after the death occurred (Rugg & Jones, 2019). Both parents should be encouraged to take opportunities as soon as possible, to discuss wishes and plans for the future when the ill-parent receives a poor cancer prognosis. Previous studies have suggested that it may be helpful for parents to involve their children in these conversations, as a child's inclusion in the decision-making can help promote positive coping and adjustment into their adulthood (Christ, 2000; Silverman & Worden, 1992; Worden, 1996). Health and social care professionals are well-placed to engage in facilitative family-centered communication when a parent is dying from cancer (Hanna et al., in press).

As parents or grandparents themselves, funeral directors reported working alongside families when a parent of dependent children has died as emotionally challenging. Other literature has reported that a funeral director often finds it overwhelming in working with families whose family circumstances are similar to the funeral director's (Forsyth et al., 2006). To support funeral directors in their provision of caring for and supporting families in the immediate bereavement period, opportunities should be available for them to manage occupational stress from exposure to emotionally charged situations (Bailey, 2019).

Despite a varied sample of funeral directors from private and public limited companies across rural and urban communities, 15 funeral directors rejected the invitation to participate in the research, partly due to a lack of experience in providing support to young families beyond the logistics of coordinating a funeral. Given that experiencing the death of a parent as a dependent child is not an unusual experience (Parsons, 2011), there appears to be a gap between helping young families navigate the immediate bereavement period with their children, and the provision of care and support provided from the funeral director. We also focused only on funeral directors' experiences of being involved with families when a parent of dependent children has died from cancer. Other illnesses such as coronary heart disease or AIDS, as well as sudden and traumatic deaths, may have different challenges and support needs for young families, to which future research should investigate.

Conclusion

Through the lens of the funeral director, this research has highlighted the distressing situation and challenges experienced by many young families in the immediate bereavement period, when a parent of dependent children has died from cancer. Funeral directors can have an important role in supporting newly bereaved families to navigate this unfamiliar experience. They might assist in equipping bereaved parents with the tools necessary to guide dependent children through the immediate bereavement period. This includes the planning of the funeral, preparing to

view the parent in the coffin, and attending and taking part in the funeral.

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Data availability

The data that support the findings of this study are available at the Ulster University Repository and available on request from the first author. The data are not publicly available due to privacy and ethical restrictions. The study passed ethical committee review [REC:17/SW/0155].

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4.6 Summary

This chapter reported the findings of the study. The first part reported the findings of parents at EOL included in the study. This was followed by the findings of bereaved parents, HSCPs and funeral directors included in the study, presented in papers format **(Papers 2 - 4)**. A number of recommendations surrounding how and when support can be best provided to parents throughout the EOL experience concerning their dependent children are provided within the study's papers. The subsequent chapter will provide a collective discussion of the findings from the four groups included in the study.

CHAPTER FIVE: DISCUSSION AND CONCLUSION

5.1 Introduction

This study aimed to explore how best to support parents, when a parent of dependent children is at EOL from cancer. While a discussion of each sample group are presented in the study's papers **(Chapter 4)**, this chapter provides an overall collective discussion of all the findings. The chapter then provides recommendations for practice, policy and education, as well as the study's strengths and weaknesses. The study's contributions to knowledge and directions for future research are also identified.

5.2 Triangulation of findings

This section will bring together the findings from each of the four sample groups for a collective discussion. Triangulating the data from parents, HSCPs and funeral directors has provided a wider and more in-depth understanding surrounding perceptions of how best parents can be supported at EOL (Noble & Heale, 2019). Triangulating the data from parents, HSCPs and funeral directors was helpful to validate the findings, and enhance the credibility of the study (Moon, 2019). Throughout this discussion, the term 'parent(s)' is referred to when the finding is representative of the data from parents at EOL and bereaved parents.

The findings are discussed under four headings: (1) communication with the children as a process, (2) coping throughout the unfolding EOL experience, (3) tension and complexities at EOL, and (4) preparing for the future.

Communication with the children as a process

There were a small group of HSCPs who had taken a lead, and steered the parents through a systematic approach of telling the children that mum or dad was eventually going to die from their cancer. However, during interviews, HSCPs did not automatically open out to saying this was something important, and certainly did not report to the researcher that this was part of their practice. In general, HSCPs had little insight into what was going on in the family home regarding who knew what, and when. From the parents perspective, they were struggling by

themselves in navigating the EOL experience with their children. While some sought out advice from a family support service or the Internet, parents muddled through challenging conversations with the children alone. While communication between the parents and children regarding mum or dad's prognosis was generally an ongoing process throughout the EOL experience, there were key conversations to be had between them at different time points. These are further discussed under three headings: (1) sharing the poor prognosis with the children, (2) telling the children mum or dad is going to die soon, and (3) preparing the children for the actual death.

1. Sharing the poor prognosis with the children

Evidenced in the parent and HSCP data, several HSCPs thought that many parents are concerned about how best to tell their children mum or dad has a poor prognosis, which in many cases, resulted in a delay from parents to telling their children that mum or dad was going to die. However, HSCPs did not intervene or explore with the parent how they were going to tell the children, and left the problem outside the caring realm.

There are many reasons that may help understand this delay provided by parents and HSCPs, and supported by the literature, including: parents' desire to protect their children from worrying about the reality of the situation (Park et al., 2015); opposing parental beliefs surrounding how and if it is best to tell the children mum or dad has a poor prognosis (Bugge et al., 2009; MacPherson, 2005); parents' uncertainty surrounding the language that is appropriate to use, as they prepare to share the news with the children that mum or dad will die (Bugge et al., 2009; Kennedy & Lloyd-Williams, 2009a; Melcher et al., 2015); and parental concerns surrounding difficult questions that may be asked from the children, such as 'are/when you going to die?' (Hockley, 2000; Kennedy & Lloyd-Williams, 2009a; Sheehan et al., 2011).

In the parent data, parents reported their need for time to 'digest' the shock of the prognosis themselves, before they considered telling the children. HSCPs did not acknowledge this as a factor, but when probed as to why parents may delay sharing the poor prognosis with the children, they perceived parents were in denial surrounding the reality of the situation. A similar

finding has been reported in the literature (Franklin et al., 2019; MacPherson & Emeleus, 2007). However, denial is defined as the rejection of a state or situation (Becker, 1997), whereas most parents reported an awareness that death was going to be the inevitable outcome. It may be appropriate to suggest that parents delay to sharing the poor prognosis with the children was impacted by the parents' emotional readiness, and not wanting to 'burden their child', rather than denial (Kübler-Ross, 1969; Park et al., 2017).

From the parent data, telling the children that mum or dad's death was going to happen was at the forefront of parents' mind, and how to tell the children this news seemed a very challenging activity, which was being avoided if possible. When HSCPs were probed as to what is important for parents of dependent children at EOL, they often reported it was finding the appropriate language to use as parents considered sharing the poor prognosis with the children. However, from the parent and HSCP data, there is a disparity between HSCPs' awareness of the needs of support and guidance for this population, and what is delivered in practice. It appeared that HSCPs generally did not address this issue with the parents, providing minimal support to them as they to navigated this journey of telling the children. Some HSCPs did not seem connected as to what was going on in the family. There were other HSCPs (mainly those with clinical experience and personal exposure to death and dying) who were on the case and had actively steered parents through this period. A similar finding has been reported in the literature (Quinn, 2003).

HSCPs lack of supportive care may be a result of a lack of meaningful engagement with parents regarding the family set-up, and ongoing conversations with them regarding their children. This is supported by the parent and HSCP data, that identified conversations between HSCPs and parents were focused on the ill-parent's cancer process and management of side effects from treatment. Other explanations provided from the HSCP data and supported by the literature include: HSCPs' perceptions that the provision of supportive care is the responsibility of another professional (Golsäter et al., 2016); HSCPs lack of understanding of what language is appropriate to the child's developmental understanding (Fearnley, 2012); and the emotional im-

pact for HSCPs to have conversations with parents who are dying regarding their children (Iranmanesh et al., 2009).

It would appear from the parent and HSCP data that withholding information surrounding mum or dad's poor prognosis from the children was an approach taken by parents to protect them from pain and upset. This finding has been reported in the two recent systematic literature reviews (Fearnley & Boland, 2017; Hanna et al., 2019). From the parents perspective, it may be suggested that they did not feel the need to share the poor prognosis with the children as they were hopeful that the parent would live longer, or be cured from their cancer.

Individuals often look to their loved one's for emotional and psychological support during a challenging life experience (Steginga et al., 2008). For dependent children, this role is usually fulfilled by their mum and, or dad (Walsh, 2007). For example, after receiving a disappointing exam result, a parent's instinct is to comfort their child and bolster self-esteem in them; as they navigate 'moving on' from the distressing experience (Pedersen, 2012). While preparing dependent children for the death of mum or dad is one of the greatest challenges that a parent can face, the same protective and comforting instincts of parenting could help facilitate a better bereavement experience for the children. Actively walking through the EOL experience with the children when the ill-parent is capable of 'parenting', provides an opportunity for mum and dad to 'parent' a child through one of the most awful life changing times their children are going to experience. If we look at the alternative, which is wait until mum or dad are actually dying, the support and parental care of telling the children mum or dad is going to die may be left to the single well-parent, who themselves is going through a highly stressed time.

Parents should be taking advantage that there is 'a window of opportunity' for them to utilise these parenting instincts, by informing the children of the reality of the situation soon after receiving a poor prognosis. From the parents perspective, this may help control for crisis management as mum or dad's death becomes imminent in the final weeks and days of life, and build

resilience for their child's future (Barnes et al., 2000; Claflin & Barbarin, 1991; Fearnley & Boland, 2019; MacPherson & Emeleus, 2007; Turner et al., 2007; Visser et al., 2004).

2. Telling the children mum or dad is going to die soon

From the parent and HSCP data, it was reported that another significant conversation between the parents and children was telling them mum or dad was actually going to die from their cancer. It appeared from the data with parents and HSCPs that this conversation often took place as the ill-parent's health deteriorated rapidly at the end, and was often navigated by the well-parent. However, from the parent data it appeared that some children, even at this dying phase, were either less, or not informed that mum or dad was going to die, despite death being imminent. From the parents perspective, it was too difficult to face this reality themselves, and so telling the children was 'making it real'. Also from the parent data, few parents seemed hopeful that God would intervene and the parent would not die, or a 'miracle' would happen. HSCPs did not report these insights as to what was happening in the parents' world as death became imminent, which may be a result of their focus on providing the physical aspects of care, and lack of engagement with the well-parent surrounding their psychosocial and spiritual needs. It seemed from the parent and HSCP data that it was 'easier' for HSCPs to provide the physical, rather than the psychological aspects of care. A similar finding has been reported in the literature (Towers & Berry, 2013).

From the parent data, one of the key uncertainties for the well-parent as they considered telling the children mum or dad was going to die, was finding the language that was appropriate to share this information. When HSCPs were probed as to what is important to parents as mum or dad's death becomes imminent, some reported parents were unsure how to tell the children mum or dad was moving to a hospice, or may not return home from hospital, or was coming home from hospital to die. However, as identified in the parent and HSCP data, there was a disparity between HSCPs' awareness of the needs of parents when death was fast approaching at the end, and what was provided in practice. Also, most HSCPs did not report this insight for parents, or did not act upon it. From the HSCP data and supported by the literature, it may be suggested

that there is a culture that has evolved of not providing psychosocial support, as HSCPs do not want to get too emotionally close to parents who are dying and have dependent children, as to do so could lead to burnout for the professional (Dencker et al., 2017; Martins Pereira et al., 2011). Other explanations may include HSCPs were too 'busy' to take the time to provide this aspect of care (Karidar et al,, 2016), or perceptions that another professional is, or already has provided it (Sprinks, 2011).

3. Preparing the children for the actual death

From the parent, HSCP and funeral director data, it was identified that a third significant conversation between the parents and children was preparing them for the actual death of mum or dad. When HSCPs were probed as to what was important for parents, as they prepared the children for the actual death of mum or dad, some suggested parents were concerned as to whether or not the children should be present in the last moments of life. In reality, findings from parents and funeral directors reported that the children were not usually present when mum or dad was actually dying. HSCPs appeared to have a lack of insight into what was happening.

The parent data suggested that as death approached, parents had not actively planned what the role of the children would look like. For parents not to have thought out how 'dying', and what role their children would have at this time suggests death 'caught up' with parents sooner than expected. Many parents reported the 'shock' of the death, that they were not expecting it. As identified in the parent and HSCP data, it may be argued that parents lack of understanding surrounding the physiological aspects of death also contributed to well-parents' disbelief that mum or dad was in the active stages of dying. A similar finding has been reported in the literature (Izumi & van Son, 2016). National EOL policy states that families should have honest and well-informed conversations from HSCPs surrounding the reality of a poor prognosis (National Palliative and End of Life Care Partnership, 2018). There is a need for HSCPs to provide parents with clear information surrounding the ill-parent's declining health, and informed, if and when possible, of clear indications where death may be imminent (Hanna et al., 2019).

From the parent data, parents seemed to have been navigating unchartered waters as mum or dad's death approached in the final weeks and days of life. From the parents perspective, it was important for them to adapt and adjust the unfolding prognosis in the family and 'live in the moment' throughout the EOL period. However, when reality 'hit' that the ill-parent was actively dying, it often became a form of 'crisis management', with significant stress placed on the well-parent to tell the children that mum or dad was going to die soon. The parent data identified how the well-parent felt ill-equipped to navigate this conversation with the children, with rapid searching for guidance from the Internet, or a family support service to navigate this conversation. HSCPs did not report this insight as to what was happening in the family when mum or dad's death became more imminent at the end.

In Western society, we have a tendency to retell the 'dying story', that may provide comfort or discomfort depending on how 'positive' the experience was (Tenzek & Depner, 2017; Wakenshaw & Silence, 2018). It may be suggested this 'crisis management' and 'falling off the cliff' experience will have a negative effect for the family (well-parent and children) in bereavement. In line with national palliative and EOL policy, if the EOL experience was better managed with an earlier intervention, or at least preparation, or offered to parents as opposed to searching for it, this could facilitate a better experience (National Palliative and End of Life Care Partnership, 2018). It has been suggested in the literature that earlier preparation in advance of the death can facilitate important moments together at the end (Back et al., 2003; Berry et al., 2001; Johnston et al., 2019); an important factor highlighted within the parent data.

If parents could understand, that by them 'taking charge' at an earlier point in the illness, when the ill-parent is still functioning at a good level (appreciating that all deaths do not follow this pattern), they should actually tell their children that mum or dad has cancer and will eventually die from it; but is not going to happen immediately. While the aftermath of this news will have a shattering impact on the children, one or both parents can 'parent' and support their children through this experience. This includes 'being there for them', and actually provide parental support that they would not receive at the end. Delaying this telling to the end, while trying to

manage a semi-conscious parent and coping with the well parents' own emotional fall out is a poor alternative.

It appeared in all data sets that there are a lack of preparations made for the children when mum or dad is actually dying. As a result, the funeral director (when they became involved) noted how the well (now bereaved) parent struggles to share the distressing news with their children that mum or dad had died in the acute post-death period. Similar communication challenges have been reported by Aamotsmo and Bugge (2014), Park et al. (2017) and Sheehan et al. (2019). From the funeral directors perspective, they are 'looking after the family in the aftermath' and 'picking up the pieces' after the parent has died. Funeral directors noted how the immediate bereavement period presents new demands and stressors for the bereaved parent, such as making preparations (in a short space of time) for the funeral. To help manage the new demands experienced by the bereaved-parent in the immediate bereavement period, findings strengthen a need for parents to be better supported and equipped before the death happens (National Palliative and End of Life Care Partnership, 2018).

Coping throughout the unfolding end of life experience

The EOL experience was a changing landscape for families, with ongoing and different needs throughout the trajectory. A number of factors appeared to be helpful for parents as they coped and navigated the EOL experience. These are discussed under three sub-headings: (1) striving for everyday ordinariness, (2) maximising social networks, and (3) 'hope'.

1. Striving for everyday ordinariness

From the parent and HSCP data, it appeared a helpful coping concept for parents throughout the EOL experience was to maintain some sense of ordinariness, despite mum or dad's declining health. This included the children going to school and attending their usual extracurricular groups, parents continuing with work, and other usual happenings in the family. Similar findings have been reported in the literature (Kennedy & Lloyd-Williams, 2009a; Lunduist, 2017). It seemed mum or dad's cancer was 'normalised' in the family, and as the prognosis

unfolded throughout the EOL period, parents were trying to adapt and adjust to continue with happenings as best as possible, such as flexible working patterns or working from home.

The parent and HSCP data identified that healthcare teams occasionally had a pivotal role in helping ill-parents continue with 'parenting', when they were physically weak and becoming frailer. For example, facilitating days out to attend an event such as a football match one of the children were playing in, when the ill-parent was receiving care in palliative care units. This allowed 'an everyday activity to happen' and brought joy to the parents. However, the findings from parents and HSCPs showed that these facilitations were rare, but were more likely to happen when a parent was in a specialist palliative care unit, rather than the acute hospital setting. When these 'outings' were facilitated by HSCPs they were much appreciated and treasured.

Literature reports that one of our main goals in life is to attach meaning to it (Frankl, 1959). It may be suggested that parents' desire for ordinariness is a coping mechanism in the search for meaning when a parent of dependent children is dying from cancer (Ellis et al., 2013b; Harrop et al., 2017). Family resilience theory highlights that having a sense of routine during an adverse situation is a protective factor in promoting security and stability for children (Walsh, 2016). It appeared parents tried to adapt and maintain some sense of routine within the family when mum or dad was at EOL, and parents should be reassured that maintaining a sense of ordinariness is helpful, as and when possible.

2. Maximising social networks

From the parent data, it appeared that frequently parents required supportive input from extended family members such as grandparents, to help with the practical aspects of parenting as a result of the demands from the unfolding prognosis. A similar finding has been reported in the literature (Hanna et al., 2019). From the parents perspective, this supportive involvement was instrumental as the ill-parent's health deteriorated, especially in the final weeks and days of life. At this particular juncture, there was often a 'lack of available parenting' from the parents, as the

well-parent's attention was primarily focused on the caring duties and spending time with the dying parent.

While HSCPs identified the final stages of mum or dad's cancer as demanding for the well-parent; juggling different roles and coping with the emotional rollercoaster of a dying spouse, these HSCPs did not refer to this period of decreased 'connection' well-parents had with their children when mum or dad was actually dying. Whereas from the parent data, parents seemed less connected with the children at this stage. HSCPs lack of insight into the actual dying stage between the well-parent and their children may be a result of them actually not knowing, as the HSCP and parent data identified HSCPs did not attend in depth to psychosocial care.

3. 'Hope'

Reported in the parent and HSCP data, it appeared that 'hope' was a concept that facilitated coping for parents throughout the EOL experience. The concept of hope at EOL has been defined as a protective factor to help a patient and their loved one's cope with an uncertain future (Duggleby, 2001). It was reported by parents and HSCPs, that parents were hopeful that treatment may prolong life. A similar finding has been reported in the literature (Golsäter et al., 2016; Turner et al., 2007). However, it was identified in the bereaved parent data that while they were hopeful treatment may prolong life, they, the well-parent, were more realistic that death was inevitable, providing reason of seeing an overall decline in the parent's health as the illness progressed.

Studies have suggested there can often be tension between parents' and between parents and HSCPs surrounding realistic and unrealistic expectations at EOL (Eliott & Olver, 2009; Johnson, 2007; Kübler-Ross, 2009; Nierop-van Baalen et al., 2016). From the parents perspective, one of the key factors that may have impacted their expectations was a lack of clear prognostic communication from HSCPs surrounding the reality of declining health. A similar finding has been reported in the literature (Breen et al., 2014; Sinclair, 2011; Sansó et al., 2015). It may be suggested that HSCPs avoided providing clear prognostic information to parents, as the reality

of telling a parent of dependent children that they were eventually going to die from cancer was too big to 'take on'; it became a more 'comfortable' position for them, the HSCP, to cling to hope of treatment in prolonging life. However, HSCPs did not acknowledge that hope centred on treatment to prolonging life would eventually place significant demands on the well-parent as death approached swiftly at the end, and reality 'hits' that mum or dad is actually going to die. To manage expectations at EOL, these findings strengthen a need for HSCPs to provide parents with clear and honest information surrounding a poor prognosis, and providing them with clear indications, when and where possible, that death may be imminent (Clayton et al., 2008; Krawczyk & Gallagher, 2011; National Palliative and End of Life Care Partnership, 2018; Nielsen et al., 2016; Walczak et al., 2014).

Tension and complexities at end of life

From the parent and HSCP data, there appears to be a tension between parents, and between parents and HSCPs in relation to the provision of supportive guidance to parents, on how best to prepare the children for the death of mum or dad. It appeared challenging for this aspect of care to be provided in routine practice, as the data from HSCPs and parents identified sometimes one parent felt the children should be informed that mum or dad is eventually going to die, and the other believed it was protecting the children from upset by not telling them. This finding has been reported in the literature (Bugge et al., 2009; MacPherson, 2005; Hanna et al., 2019). As identified in the HSCP data and supported by the literature, HSCPs may have lacked confidence, skill and time to facilitate conversations between parents on how best to support their children, when one of them was dying from cancer (Fearnley, 2012; Punziano et al., 2017). It would appear that often the well-parent was 'ignored' during clinical visits, as the parent and HSCP data identified how conversations were predominately directed to the ill-parent and focused on aspects of their care. Furthermore, as identified in the parent and HSCP data, it was the well-parent navigating difficult conversations with the children, such as telling them mum or dad is going to die, and when the parent was actually dying. These findings strengthen a need for a family-centred care in practice (Franklin et al., 2019; Hanna et al., 2019).

While it appeared from the parent data that parents felt 'shortchanged' surrounding a lack of supportive guidance from HSCPs regarding their children, the HSCP data identified the provision of this care as a challenging aspect of their role. One of the key obstacles perceived by HSCPs to impact their provision of supportive care to parents at EOL concerning their children was the perception that conversations surrounding a dying parent's children would be too emotionally distressing for them, the HSCP. A similar finding has been reported in the literature (Iranmanesh et al., 2009; Kaup et al., 2016; Wilkes & Beale, 2011). A systematic review reported that some studies suggested HSCPs having children of similar ages as the parents they are caring for was a facilitator towards HSCPs' provision of guidance to them at EOL regarding their children, whereas other studies suggested it was a barrier (Franklin et al., 2019). Research exploring the concepts of perspective taking, empathy and helping behaviours suggest support is more likely to be offered when the provider can 'emotionally put themselves in the shoes' of the recipient requiring support (Lamm et al., 2007). It would appear that for many HSCPs this was not the case.

Seed and Walton (2012) suggested to support HSCPs' provision of caring for patients at EOL, they need to mentally disengage themselves outside of their professional roles to promote their own mental well-being. Although a conclusion that is likely to be true, personal and professional identity are two-fold and should not be considered in isolation (Inglebretsen & Sagbakken, 2016). Reported in the HSCP data and supported by the literature, it may be suggested that a lack of family-centred care in practice was also due to a lack of supportive working environments to offload the emotional impact of having challenging EOL conversations with parents of dependent children (Wilkes & Beale, 2001). Literature suggests when HSCPs are provided with appropriate supervision it can promote their resilience to undertake challenging aspects of care (such as having difficult EOL conversations) (Dencker et al., 2017), reduce burnout (Martins Pereira et al., 2011; Melvin, 2015; Wallbank & Hatton, 2011), and promote job satisfaction in cancer and EOL care (Edmonds et al., 2015; Payne, 2001). Other explanations reported in the data and supported by the literature include HSCPs lack of knowledge on how best to provide parents with

appropriate support in relation to the children (Fearnley, 2012), as well as a lack of understanding on whose role it is to provide this aspect of care (Golsäter et al., 2017).

Preparing for the future

Data from parents and funeral directors acknowledged the importance of making preparations for the future before the parent died, as a supportive measure for the family moving forward after the death. This included outlining funeral wishes, sorting out finances, passwords on accounts, and mortgages. Similar findings have been reported in the literature (Bouchal et al., 2015; Caserta et al., 2019; Coelho & Barbosa, 2017; Durepos, 2020; Supiano et al., 2020). Most bereaved parents stated that they were not practically prepared for 'life' after the parent had died, but would have liked to have been. From the parents perspective and supported by the literature, it was too difficult for them to consider making preparations for after they, or their spouse had died (McLeod-Sordjan, 2014). Making preparations for the future was less prioritised for parents as it went against their hope of treatment in prolonging life, or hope that a cure would have been available (Back et al., 2003); thus feeling preparations (if any) would happen later. Also, it may be suggested that HSCPs are not providing clear information for parents surrounding the importance of making preparations for the future, with vague language such as 'putting your affairs in order' (Kennedy & Lloyd-Williams, 2006).

For those parents who did have the ongoing and open conversations about the fact that mum or dad was going to die, this allowed for discussions to happen from the children, like 'what will we do if I need to get a costume for Halloween', 'who's going to repair things around the house now', or 'are you going to be in a coffin', or were even part of the decision making on how time was going to be spent together as a family during those last months. These open conversations could only happen if the prognosis was acknowledged and integrated into the ongoing situation.

When probed as to what is important for families when a mum or dad is at EOL from cancer, HSCPs did not report insight into the importance for parents to make preparations for the

future before the ill-parent died. Policy highlights patients with advanced progressive conditions should be encouraged and supported by HSCPs to manage practical and financial affairs at EOL (National Palliative and End of Life Care Partnership, 2018). From the HSCPs' perspective, they may have perceived this aspect of care was the role of another professional. A similar finding has been reported in the literature. To prevent a cumbersome legal and financial process for the well-parent after the parent dies, there is a need for HSCPs to recognise a pivotal role they can have to advise parents to take opportunities to make preparations for the future, when the ill-parent is still well enough (Bouchal et al., 2015; Caserta et al., 2019; Lundquist, 2017).

From the parent and HSCP data, it appeared that some HSCPs were encouraging parents to engage in memory activities, such as writing letters for the future and memory boxes, to help aid the child's connectedness to the parent for after they have died. A similar finding has been reported in the literature (Bugge et al., 2009; 2014; MacPherson & Emeleus, 2007). While some parents did engage in these activities, in reality it was too painful for parents to consider not being around for their children. This insight was not considered by HSCPs. It may be argued that encouraging parents to engage in memory activities can turn into an experience of sadness, as the activities 'are for the future' (Odelius et al., 2014). However, as identified in the HSCP and parent data, it was important for parents to continue living in the 'here and now'; such as walking the dog and getting an ice-cream with the children, or other happenings such as getting to their child's sport's day. These findings suggest it may be appropriate if HSCPs encouraged parents to take each day at a time and to focus on the present, and incorporate the things that they enjoy as a family (Clayton et al., 2005), rather than the background pressure of engaging in 'memory activities'.

Summary

This section provided an overall discussion of all the findings. Findings from the parent and HSCP datasets identified that parents would benefit from supportive guidance from HSCPs as they prepare to tell their children mum or dad has a poor prognosis, and is going to die. Despite HSCPs' awareness of the needs of this population, findings identified family-centred care is

often inadequate in practice. For parents, it was important to adapt and adjust the illness in the family, to 'live in the moment', and place hope on treatment to prolong life until a cure became available. Significant demands were placed on the well-parent as the ill-parent's health rapidly deteriorated at the end, such as having to tell the children mum or dad is going to die. However, the data showed that if parents could tell the children early in the journey, when the dying parent is 'well', this parent could be actively involved in 'parenting' their child through this great life changing event, sharing the sadness and providing love and support that only a parent can. It was identified the funeral director ended up 'picking up the pieces' after the death in the immediate bereavement period, as a result of a lack of supportive input from HSCPs at EOL. There is a need for parents to be advised and encouraged to make earlier preparations to control for 'crisis management', as death becomes imminent in the final weeks and days of life.

The next section of this chapter reports how the findings from this study are relevant to Walsh's (2016) family resilience theory.

5.3 Evidence of the findings from this study to Walsh's (2016) family resilience theory: processes of coping in an adverse situation

This study has provided supporting evidence surrounding how the processes associated with positive coping in Walsh's (2016) family resilience theory could be best promoted in parents, when a parent of dependent children is at EOL from cancer. These are summarised in Table 4.

Table 4: Summary of how the findings map on to Walsh's (2016) family resilience theory

Process	**Evidence from the current study**
Normalising the adverse situation within the home	- This study highlighted the need for parents to provide their children with open and honest communication surrounding mum or dad's poor prognosis and declining health. - Recommendations have been provided concerning how parents could prepare to share the difficult news with the children that mum or dad is going to die and when the parent has died. - Parents reported (to the best of their ability) maintaining usual routine and structures within the family despite the ill-parent's declining health. Alongside this, parents reported experiencing satisfaction from the usual happenings in the family, rather than elaborate plans of chasing after dreams. - Through the lens of the funeral director, this study reported how parents could best navigate the distressing immediate bereavement period with the children, and involve them in aspects of the planning and delivery of the funeral, as well as preparing the children to view their parent in the coffin.
Having a positive outlook surrounding the stressor	- This study highlighted a need for parents to forward plan as a protective means of securing the family's financial future. - Parents reported their importance of maintaining hope in treatment throughout the EOL experience. In this context, hope can be considered as cherishing each day together as a family and hopeful that death will not be so imminent. - Spiritual and, or religious beliefs were important for parents throughout the EOL experience, with parents finding great strength and hope that a higher power will 'take care' of the family, despite the reality of the situation. On occasions, this hope was unrealistic, such as being healed from a faith perspective. - Findings highlighted parents importance of making the most of ordinariness when mum or dad is dying from cancer. For most parents, it was 'living in the moment' and experiencing satisfaction from the usual family happenings, despite the ill-parent's declining health. For few parents, there were opportunities (practically and financially) to have more elaborate plans, such as going on a foreign holiday, but for more it was cherishing the usual happenings in the family.

Process	Evidence from the current study
Fostering a sense of spirituality	- It appeared faith was important to some parents 'in making sense' of the reality of the situation. - Faith was also a comfort for many parents that the parent would no longer be suffering, and a higher power would 'take care' of the whole family; often referred to as 'God's plan'. - While the findings highlighted the importance of explaining the biological underpinnings of death to the children, some parents exercised the family's religious or spiritual belief to explain death to their children (i.e. they would see the parent again).
Being flexible to reorganising structures when needed	- Parents were trying to adjust and normalise the poor prognosis within the family; striving to maintain routines for the children to the best of their ability. This included changes to working schedules such as working from home or part-time working, to accommodate new schedules to the routine such as getting treatment. - This study highlighted the importance for parents to avail of social networks to help manage the practical aspects of parenting at EOL, to ensure the child's routine was maintained. This was especially evident as the ill-parent's health deteriorated towards EOL and the well-parent's attention was focused to spending time with, and caring for the ill-parent. - HSCPs highlighted that some well-parents had to adapt to new roles as a result of the ill-parent's declining health. - HSCPs can have an important role in helping parents obtain practical and/or financial support when structures or roles change in the family when mum or dad is dying from cancer.

Process	Evidence from the current study
Maintaining connected to each other	- Children and parents have reported their desire to spend quality time together when mum or dad is dying to create memories and a 'connection' for the future. Meaningful time together was usually captured through the usual happenings, rather than expended energy of chasing after dreams. - Parents reported a keenness to capture the everyday happenings through photographs or digital recordings. Given the physiological changes associated with the ill-parent's declining health, these were usually taken in the 'early days'. - Parents reported their importance for uninterrupted family time together when the ill-parent was actively dying to cherish final moments together as a family. - Funeral directors suggested including children in the planning and delivery of the funeral, as well as adding something inside the coffin with the parent is helpful for children to keep connected with their dead parent, feeling they are part of the 'saying goodbye', and part of them would be with the parent 'where they would go'.
Availability of social networks when required	- Attending school was helpful for children to spend time with peers and friends, and have emotional release from the distressing situation at home. - Meeting other families going through a similar experience was suggested helpful for parents and children in knowing 'they are not alone' in this EOL experience. - Availing of social networks appeared helpful for parents to manage the day to day aspects of parenting, particularly when the ill-parent's health deteriorated towards EOL when their focus was directed to the caring duties and spending time with the dying parent.

Process	Evidence from the current study
Clear communication within the home regarding the stressor	- This study highlighted parents require clear information surrounding the ill-parent's poor prognosis from HSCPs, and provided with clear indications when the ill-parent's health is declining towards EOL. It was suggested a lack of clear information surrounding mum or dad's illness left parents feeling ill-equipped to explain the complexities of the parent's poor prognosis to the children. - Children desire for clear information surrounding their mum or dad's poor prognosis, regularly provided with updates surrounding treatment and declining health, and informed when death is imminent. - There is a need for parents to be encouraged that some preparation is necessary for the children surrounding mum or dad's poor prognosis, as their health could deteriorate at any time and the parents may be less able to support the children at this time. - Parents often require support on how best to tell the children mum or dad is going to die soon and when the parent has died. This should be incorporated as part of HSCPs role when the ill-parent's health deteriorates towards EOL. - HSCPs can have a key role to encourage parents to tell the children mum or dad is going to die, and provide them with guidance and language as they prepare to share this news with the children. - To prepare children for the events associated with the immediate bereavement period, the bereaved parent should provide their children with factual details of what they will see and do.

Process	Evidence from the current study
Opportunities to share emotions openly	- Parents should be encouraged to foster an environment of open and honest communication regarding the situation with the children; inferring a two-way process between the parents and children regarding mum or dad's declining health. - It has been suggested where there is a lack of open communication regarding the ill-parent's declining health, children often feel reluctant to voice their emotional, practical and mental concerns. - There is a need for parents to have difficult conversations together surrounding the reality of the poor prognosis and make preparations for the future while the ill-parent is still well. HSCPs should advise parents to make these preparations when they receive the poor prognosis.
Shared decision-making	- Parents should be reassured that telling the children the reality of the situation is protecting them. Also, they should be encouraged to share the news with them that mum or dad has a poor prognosis as soon as possible, provide them with regular updates surrounding their parent's declining health, and include them in key decisions surrounding mum or dad's care and the future. - This study highlighted the importance of including the children in the ill-parent's care and being a part of the EOL experience. - To aid preparedness for the death of mum or dad and facilitate a better bereavement experience for the family, parents should be encouraged by HSCPs to forward plan for the future soon after receiving a poor prognosis. This includes practical matters such as wills, finances, updating passwords on accounts or legalising guardianship for the children. This also includes those parents who desire to engage in memory activities such as memory boxes or writing letters for the future, as their health may deteriorate quickly at EOL and be less able to engage in these tasks at that point. - Findings reported the value of including the children in the planning and delivery of the funeral.

5.4 Recommendations for practice, policy and education

This section discusses important recommendations for the areas of practice, policy and education.

Practice

The following section provides important implications for practice. These are discussed under five headings: (1) the need for clear and honest information surrounding the reality of a poor prognosis, (2) the importance of early preparation when a parent is dying from cancer, (3) making the most of ordinariness to aid coping, (4) the need for family-centred care at end of life, and (5) encouraging parents to involve the children in the immediate bereavement period.

1. The need for clear and honest information surrounding the reality of a poor prognosis

There is a need for HSCPs to provide parents with clear and honest information surrounding a poor prognosis, to ensure they understand the severity of their condition and have realistic timescales. Parents should have an awareness that death will be the inevitable outcome from the poor prognosis. HSCPs should provide parents of clear indications when, and where possible of a declining situation and where death is imminent, so parents can prepare the children for the actual death of their mum or dad.

2. The importance of early preparation when a parent is dying from cancer

At the time of receiving the poor prognosis, HSCPs should acknowledge with parents how difficult it will be for them to share the news with their children that mum or dad is going to die from cancer. HSCPs should reassure parents that by telling the children the reality of the situation, they are protecting their children. Parents should be encouraged to share the difficult news with the children as soon as possible, as children will know that something is wrong and knowing the reality of the situation can help them feel supported and secure at a distressing time. Parents should be advised that earlier preparation provides them with an opportunity to comfort their children and absorb the pain which may facilitate long-term coping and psychosocial adjustment.

Parents should be encouraged to avoid providing the children with unrealistic expectations such as surviving the cancer, but ensure the children understand the reality of the poor prognosis that the parent will eventually die. It is essential that HSCPs equips the parents to use plain language (actually give language examples) with the children when sharing the news with them that mum or dad is going to die, using terms such as 'cancer' and 'dying'.

While it is difficult to predict when the death will happen, parents should reassure the children that they are going to 'take one day at a time and make the most of everyday'; we have 'here and now'. It would be helpful for HSCPs to reassure parents that children may not always respond in the expected way such as crying, and to encourage parents to reassure the children that they are loved and offer them the opportunity to ask questions. HSCPs should have an awareness of the service provision offered by organisations that provide family support, and tailor referrals for families with psychosocial needs.

As the ill-parent's health deteriorates towards EOL, if and where appropriate, HSCPs should reassure parents to provide the children with the choice to be present when the ill-parent is actively dying. It would be helpful if HSCPs informed parents of the physiological changes associated with dying and provided them with appropriate language, as they prepare their children for the death of their mum or dad.

HSCPs should advise parents to forward plan for the future at the time of receiving the prognosis, or in the early days or weeks when the parent is still well. It would be prudent to reassure parents that now would be the best time to have difficult conversations, or make plans surrounding the future; as the parent's health could deteriorate at any time and may not have the opportunity to do so. Parents should be reassured that forward planning can provide comfort to the family after the parent has died, that they are 'fulfilling their wishes' and aiding security for the future. Forward planning may include outlining funeral wishes, managing finances, legalising

guardianship for the children (perhaps in situations of divorce, separation or absent well-parents) and having difficult conversations surrounding future aspirations for the well-parent and child.

3. Making the most of ordinariness to aid coping

HSCPs can have an important role to fostering a sense of coping in parents at EOL, by reassuring them there is now, this moment, to be lived together as a family. Parents should be encouraged by HSCPs to capture the moments together as a family, by making the most of 'good days' when the ill-parent feels well, by doing the things they enjoy most as a family. This may include usual happenings such as walking the dog to the park and getting ice cream.

4. The need for family-centred care at end of life

There is a need to promote HSCPs' awareness of family-centred care and the challenges faced by many parents, as they prepare their children for the death of mum or dad. HSCPs should recognise that they can have a pivotal role to guide and support parents through this period when there are heightened needs. In particular, ensuring that the needs of parents and their children are being catered for throughout the EOL experience, which includes the children being informed surrounding mum or dad's declining health. HSCPs should take a lead in opening conversations with both parents, if possible, at EOL concerning the children, to identify their needs as they prepare the children for the death of a parent. It is pertinent that the provision of this care is provided to both the ill and well-parent; as either parent could be taking a lead role in sharing information with the children surrounding mum or dad's declining health. Also, providing this care and support to both parents could encourage them to have difficult conversations concerning the future.

Parents should be encouraged to maintain routine such as the children going to school, and to draw upon social networks to help with the practical aspects of parenting if and when needed. HSCPs should identify and help parents with ongoing practical, financial and physical needs at EOL that may impact their ability to carry out the parenting role. There is a need for flexible visiting periods within the acute setting when a parent of dependent children is receiving

inpatient care, as visiting hours are often unsuitable for parents with dependent children as a result of coinciding with school and meal times for their children.

To enhance the provision of family-centred care, HSCPs should be provided with regular clinical supervisions to offload the emotional impact of providing care and support to parents of dependent children, when mum or dad is dying from cancer. Discussions surrounding issues associated with parenting dependent children at EOL should also be promoted within the healthcare setting, to provide opportunities for learning and peer-support concerning how best to care for parents of dependent children when one of them is dying from cancer. Promoting a culture of 'normalising' conversations regarding death may promote HSCPs confidence, in their provision of family-centred care when a parent is dying from cancer.

5. Encouraging parents to involve the children in the immediate bereavement period

Part of the EOL care should include preparation from HSCPs surrounding the death and immediate following days. It would be in the best interest for parents and children that this has been talked about, or at least thought about. This could include: what they are going to say to the children and how the children may be involved. Appreciating that cancer deaths can be different, there can be a sense of 'how it may look'. What is known is that there will be the parent who has died, and how the next few days will 'pan out'. For example, are the remains going to a funeral home or possibly waked at home, and what role will the children have during this time.

As many funeral directors appear to have an important role in the acute post death period, this study recommends that funeral directors have a systematic approach of providing care to families in the immediate bereavement period, when a parent of dependent children has died. This includes reassuring and encouraging parents their children can be involved in the planning of the funeral such as choosing the music and flowers for the service or choosing the deceased parent's outfit for the coffin. Also, encouraging the parent to involve the children in the delivery of the funeral, such as giving a reading or poem during the service or throwing a flower into the grave. Funeral directors should also reassure the parent that the children can be present within

the home during ‘the wake’ and the children can view the parent in the coffin. Funeral directors can have an instrumental role in providing parents with guidance, as they prepare their children for this viewing. This includes encouraging parents to provide the children with factual details of what they will see (i.e. what the coffin will look like and how the body will look, feel and be positioned), and encouraging the children to add something inside the coffin with the parent such as a letter or picture to provide them with a purpose of viewing. Funeral directors should also encourage parents to nominate an adult to each of the children on the day of funeral, in the event of the children being separated from the parent. To support funeral directors provision of this aspect of care, opportunities should be available for them to offload the emotional impact of providing a service to families when a parent of dependent children has died.

The next section provides recommendations for the area of policy.

Policy

This section offers recommendations for the area of policy. These are discussed under two headings: (1) family-centred care, and (2) regulation of the funeral directing role.

1. Family-centred care

Policymakers should recognise the importance of involving children in EOL care when a parent is dying from cancer. The National Institute for Health Care Excellence (NICE) only acknowledges support to parents at EOL concerning the children. However, literature purports that providing family-centred care at EOL helps promote better psychosocial adjustment for children in bereavement. Promoting better health outcomes for the children when a parent is at EOL may have potential benefits in terms of fewer referrals to bereavement support or mental health services after the parent has died, with further benefits surrounding costs to the health service (Colizzi et al., 2020; Stroebe et al., 2007). There is a need for policymakers to incorporate this important aspect of care as part of the HSCP role, and guidelines should be made available to support their provision of this care in practice.

2. Regulation of the funeral directing role

A Code of Practice should be developed for funeral directors to provide them with an accountability structure surrounding their 'professional' role in the United Kingdom. Policymakers should be cognisant that funeral directors are usually the only 'professional' available to help guide newly bereaved parents through the immediate bereavement period, when a parent of dependent children has died. This study identified a supportive role funeral directors can have in relation to encouraging parents to involve the children in the planning and delivery of a funeral, and providing supportive guidance to them as they prepare their children to view the parent in the coffin. The provision of this care from funeral directors has the potential to mediate for adverse outcomes for the children into adulthood, facilitating better psychosocial adjustment (Holland, 2004). A Code of Practice should acknowledge the pastoral role of the funeral director, and outline the care they should be offering to parents, when a parent of dependent children has died.

The next section provides recommendations for the area of education.

Education

This section reports important recommendations for the area of education. These are discussed under two headings: (1) family-centred care, and (2) pastoral role of the funeral director.

1. Family-centred care

There is a need for HSCPs who provide care to cancer patients at EOL to have an awareness on the importance of providing family-centred care, when a parent of dependent children is dying from cancer. Alongside this, HSCPs need to be equipped with the knowledge and skills that promotes their confidence to deliver this necessary care. HSCPs should therefore be offered training that informs them of the needs of parents with dependent children, when mum or dad is dying from cancer. Training should provide HSCPs with the 'language' to offer parents as they prepare to have significant conversations with the children, to include the telling of the poor prognosis, preparing them for the actual death and when the parent has died. The recommendations provided under the section 'Practice' should inform this training.

2. Pastoral role of the funeral director

Training should be made available for funeral directors to inform them of the challenges encountered by newly bereaved parents, when a parent of dependent children has died from cancer. Funeral directors should recognise that they can have an important role in guiding the newly bereaved parent through the distressing immediate bereavement period. It would be helpful for funeral directors to have an awareness of what and how they can support newly bereaved parents, as they support their dependent children during the immediate bereavement period. Examples of how funeral directors can help parents navigate the immediate bereavement period with their children are detailed in **Paper 4**.

The next section reports the strengths and limitations of the study.

5.5 Strengths and limitations

This section reports the study's strengths and limitations.

Strengths

Previous research exploring the experiences of parents of dependent children when mum or dad is dying from cancer are largely representative of mothers with advanced breast cancer attending support groups (Hanna et al., 2019). A key strength of this study has been recruitment of participants not only across a range of tumour groups, but also fathers at EOL *(n3)*, bereaved mothers *(n12),* and bereaved fathers *(n9).* The experience for parents as they prepare their children for the death of a parent has also been captured through the lens of a range of HSCPs *(n32)* and funeral directors *(n23)* who can have instrumental roles in facilitating support to parents concerning their children at EOL and the immediate bereavement period that follows. It can be argued that the inclusion of HSCPs and funeral directors to this study provides a greater understanding of the variation of experiences of parents, as they navigate the EOL period with the children; to include some of the challenges faced by parents impacted by divorce or separation.

This study made attempts to recruit parents beyond family support services. Compared to studies that have been unable to recruit parents outside of support groups (Hansen et al., 2017; Sheehan, 2010), it may be argued that this study had relative success in recruiting parents through the public advert. The inclusion of parents outside of support groups was helpful in understanding how parents navigated the EOL experience in the absence of direct involvement with family support workers. Also, the literature is often unclear where the ill-parent is on their illness trajectory (Hanna et al., 2019), whereas this study provided clear definitions of EOL and the immediate bereavement period.

The interviews with HSCPs were conducted and analysed by the researcher, who does not come from a healthcare background. As a result, the researcher had less preconceptions surrounding HSCPs role in providing supportive care to parents at EOL, which was helpful in the control of bias in conducting these interviews and analysing the data (Hopf, 2004). A team-based approached to defining themes strengthened the study's rigour and trustworthiness (Rolfe, 2006).

Contacting the first author of included articles to the systematic review was useful in identifying literature that was not indexed on electronic databases. This method of grey literature searching led to networking opportunities and the establishment of a partnership with a team of researchers at King's College London.

Limitations

A number of limitations are provided within the study's papers. This section will outline additional limitations.

Participants where recruited from Northern Ireland, which is a national less ethnically, spiritually, culturally diverse and has low Black, Asian and Minority Ethnic (BAME) populations (Northern Ireland Statistics and Research Agency, 2011). It is possible the needs of those from BAME communities are different and are unaccounted for in this study (Bornstein, 2012).

The decision was taken to place the public advert in a newspaper that had the potential to target more parents, and was cost-effective. It may be suggested the national newspaper selected was not the most suitable method to recruit hard to reach parents at EOL. It could have been appropriate to advertise the invitation to participate in the study within free newspapers that are distributed to neighbourhoods associated with lower socio-economic status and educated backgrounds (Somerville, 2001).

From an ethical perspective, parents identified as eligible to participate in the study from the family support service and hospice were invited to opt-in to the research as opposed to opt-out; with a letter from the appropriate gatekeeper (Bellman et al., 2001; Lai & Hui, 2006; Steeves et al., 2001). While many parents may have chosen not to participate as a result of the emotive topic, a letter may have been an impersonal approach to recruitment. A more suitable method may have been a personal telephone conversation between the gatekeeper and the parent (Page et al., 2006; Sinclair et al., 2012). This approach may have 'gently' promoted participation to the study as it was a personal invitation (Page et al., 2006). Also, some parents may have been willing to participate, but as the letter required a response, it may have been less prioritised to return and was forgotten, as no follow-up took place.

The next section reports the study's contribution to knowledge.

5.6 Contributions to knowledge

This study has made contributions to knowledge through peer-reviewed publications in journals accessed by professionals who provide care and support to parents at EOL, presentations at local events, and international conferences. The findings of this study will also be shared at upcoming international conferences. Alongside a team of researchers at King's College London, a resource is currently being developed to support HSCPs' provision of supportive care to parents regarding their dependent children, when mum or dad is dying from cancer. This resource will be endorsed and hosted by Marie Curie Hospice, and is expected to be launched as part of

the seminar series at the European Association of Palliative Care's World Congress, October 2021.

This study has provided a better understanding of the experience for parents as they prepare their children for the death of a parent and the immediate bereavement period that follows, through the lens of parents, HSCPs, funeral directors and a systematic review of the literature. The findings aid our understanding surrounding how parents navigate family life when mum or dad is dying from cancer, to include trying to adjust and normalise the unfolding poor prognosis within the family, striving to maintain normality and routine, the need for social networks to help with the practical aspects of parenting - particularly as the ill-parent's health declines in the final weeks of life, and the importance of making the most of ordinariness and 'living in the moment' when mum or dad was dying from cancer. The inclusion of mothers and fathers to this research identified how sharing information with the children surrounding the ill-parent's declining health was usually shared by the parent that took the predominant role in parent; strengthening a need for family-centred care. The findings highlight the need for parents to be encouraged to forward plan for the future; to facilitate ease and comfort for the family after the ill-parent has died **(Paper 2)**.

This study reported how HSCPs across a range of specialist and generalist roles in acute and community settings experience and perceive their role in providing care and support to parents at EOL concerning dependent children. A key finding was that such care and support to parents regarding the children was often lacking in routine practice. Alongside this, the findings highlighted the complexities HSCPs are confronted with as they care for parents at EOL. Recommendations have been provided as to how, what and when HSCPs should provide support to parents at EOL regarding the children. In particular, supporting parents as they prepare to have difficult conversations with the children such as telling them mum or dad is going to die, and when they are actually dying. Also, findings identified an instrumental role HSCPs can have surrounding the provision of financial and practical support to parents at EOL **(Paper 3)**.

This study highlighted a number of challenges faced by the bereaved parent in the immediate bereavement period after the ill-parent has died. Funeral directors can have an instrumental role in guiding the newly bereaved parent through this distressing period, in particular encouraging and reassuring parents to involve the children in the planning and delivery of the funeral, as well as viewing the parent in the coffin **(Paper 4)**.

The next section provides some directions for future research.

5.7 Directions for future research

Future research should include a longitudinal study that would follow families on regular intervals, to explore the experiences of the parents and children throughout the EOL period and into bereavement. This would allow insights as to how parents could best navigate the ongoing EOL experience from different perspectives. To better understand the needs of this population, such longitudinal studies should take demographic factors into consideration such as families impacted by divorce and separation and socioeconomic status. Research should also consider the needs of other caregivers such as grandparents, who may be one of the main caregivers of the children when a parent is at EOL from cancer and after the parent has died.

While the findings of this study are currently being developed into a resource for HSCPs in partnership with a team of researchers at King's College London, it should be evaluated in terms of its acceptability and feasibility as a resource. Also, the resource should be evaluated in terms of increasing HSCPs' self-efficacy in their provision of supportive care to parents concerning their children when a parent is dying from cancer. Subsequent studies should investigate if the resource has impacted HSCPs' provision of caring and supporting for parents at EOL from cancer. A similar resource could also be developed and evaluated for funeral directors, to support their provision of supporting the bereaved parent in the immediate bereavement period when a parent of dependent children has died.

Children spend a significant proportion of time at school, and literature has suggested that children's vulnerable emotions surrounding the impact of mum or dad's impending death are often displayed within the classroom (Goldman, 2017). Alongside this, many studies have reported that the professionals working within the school environment, to include the child's teacher and classroom assistants, often feel ill-equipped to talk about death and dying within the classroom (Kahn, 2013) or how to respond to children's vulnerable emotions concerning their grief (DeMuth et al., 2020). There is a need to better understand a role the child's school can have in facilitating family support, and the obstacles faced by professionals working in school settings when a student's parent is dying from cancer; to understand how best the school can be equipped to support the children, parents and peers within the child's class, when a parent is at EOL from cancer.

5.8 Conclusion

There are few experiences more difficult for parents than preparing their dependent children for the death of mum or dad. Parents often require guidance surrounding how best to support their children when mum or dad is dying from cancer.

Through the lens of parents, HSCPs and funeral directors, this study highlighted the intricate complexities experienced by many parents of dependent children, when mum or dad is at EOL from cancer and the subsequent immediate bereavement period that follows. Key challenges included: parents emotional readiness to tell the children mum or dad was going to die from cancer, opposing parental beliefs surrounding how best to support the children when mum or dad was at EOL from cancer, and parental uncertainty surrounding their child's involvement in the rituals that take place in the immediate bereavement period.

Despite parents' desire for supportive guidance from HSCPs surrounding how best to prepare their children for the death of mum or dad, finding highlighted the provision of this care is often inadequate in practice. Findings identified obstacles to HSCPs' provision of supportive care to parents at EOL concerning their children included: perceptions that conversations with

dying parents regarding their children would be too emotionally distressing, a lack of confidence and knowledge to provide instructive support, and a lack of time and privacy to provide meaningful support.

Findings identified parents sought guidance and support from the funeral director regarding the children once the parent has died in the immediate bereavement period. This support was instrumental in the absence of supportive care from HSCPs at EOL, and when the period between poor prognosis and death was as short as days and weeks. Findings highlighted funeral directors can have an instrumental role in guiding the bereaved parent through the distressing immediate bereavement period. This includes reassuring and encouraging parents that children can meaningfully be involved in the planning and delivery of their mum or dad's funeral, and view the parent in the coffin. Funeral directors can have a pastoral role in equipping parents with guidance and language as they prepare their children for the events that take place in the immediate bereavement period. Guidelines and training should be developed to incorporate this aspect of pastoral care to the funeral directing role.

This study identified a number of factors that may help provide a better pre and post death experience for the family. This included a need for HSCPs to provide parents with clear and honest information surrounding a poor prognosis and inform them of clear indications when, and where possible of a parent's declining health at EOL. Also, HSCPs should encourage parents that some preparation for their children surrounding mum or dad's declining health is necessary, and to advise parents to make preparations for the future soon after receiving the poor prognosis; as the parent's health may deteriorate quickly at any time and may be less able to do so at that time. HSCPs should encourage parents to make the most of their time together as a family and do the things they enjoy most as a family when the ill-parent is still well. The ill-parent's declining health and caring needs may pose additional demands to the family's usual routine; therefore it would also be helpful for parents to be encouraged to maximise social networks available to them to help with the practical aspects of parenting at EOL when needed. There is a need for HSCPs to recognise the pivotal role they can have in supporting parents of dependent children

when mum or dad is at EOL from cancer, and for training and guidelines to be developed to support their provision of supportive care to parents of dependent, when mum or dad is dying from cancer.

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Appendix A

Invitation to participate in research

Are you a parent with a poor cancer prognosis or have lost your partner to cancer and have children under the age of 18?

We would like to invite you to take part in a one-to-one interview to hear about your family needs during this time

It will take approximately one hour

When & Where: At a time and place convenient for you

Why: By talking to you about your experiences we hope to improve the support we give others in the future

If you would like more information or wish to participate in this research please contact Jeff Hanna from the family centered care team on 07707407085 or hanna-j25@ulster.ac.uk

Appendix B

ELFAST TELEGRAPH FRIDAY AUGUST 17 2018

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NEWS

LUCY MAPSTONE

Tributes to Queen of Soul Aretha, 'a singer who defined the American experience'

ETHA Franklin, the Queen of
l, has died aged 76.
The singer, whose career has
anned seven decades, died at
home in Detroit, Michigan,
.50am yesterday, her publi-
said.
statement from Franklin's
ily, via the singer's long-time
ficist Gwendolyn Quinn, said
t she died "surrounded by
ily and loved ones".
The statement continued:
anklin's official cause of death
due to advance pancreatic
cer of the neuroendocrine
e, which was confirmed by
anklin's oncologist, Dr Philip
lligs of Karmanos Cancer In-
ute in Detroit, MI.
"In one of the darkest mo-
nts of our lives, we are not
le to find the appropriate
rds to express the pain in our
art. We have lost the matri-
h and rock of our
mily. The love she
l for her chil-
en, grandchil-
ren, nieces,
phews, and
anins knew
bounds.
"We have
en deep-
touched
the in-
redible
utpour-
g of love
nd sup-
rt we have
ceived from
ose friends, sup-
orters and fans all
round the world. Thank you
r your compassion and prayers.
"We have felt your love for
eretha and it brings us comfort
know that her legacy will live
n. As we grieve, we ask that you
espect our privacy during this
difficult time."
Quinn added that "funeral ar-
rangements will be announced
in the coming days".
The music icon, known for her
hits such as Respect, Think and
(You Make Me Feel Like) A Nat-
ural Woman, died several days
after she was reported to be se-
riously ill.
In recent days, the ailing star
had been visited by Stevie Won-
der, the Rev Jesse Jackson and
her ex-husband, actor Glynn Tur-
man.
Heartfelt tributes came from
both the entertainment and po-
litical worlds.
Former US President Barack
Obama and his wife Michelle
said "we were all graced with a
glimpse of the divine" every time
Franklin sang.
"Through her compositions
and unmatched musicianship,
Aretha helped define the Amer-
ican experience," they said in a
joint statement.
"In her voice, we could feel
our history, all of it and in every
shade, our power and our pain,
our darkness and our light, our
quest for redemption and our
well-won respect.
"She helped us feel more con-
nected to each other, more hope-
ful, more human. And sometimes
she helped us just forget about
everything else and dance."
They went on: "Aretha may
have passed on to a better place,
but the gift of her music remains
to inspire us all.
"May the Queen of Soul rest
in eternal peace. Michelle and

Top: Aretha Franklin sings before President Barack Obama and First Lady Michelle Obama at the dedication of the Martin Luther King Jr. Memorial in Washington in 2011. Above left: Aretha arriving with husband Glynn Turman and son Kecalf (R) for the couple's wedding reception in a Los Angeles hotel in 1978 and (right) the singer at the microphone in 1972

CHARLES CHAPMAN/CBS/PLAC/APPHOTO

I send our prayers and warmest sympathies to her family and all those moved by her songs."

Sir Elton John was among the first of Franklin's peers to pay tribute following her death.

He called her death a "blow for everybody who loves real music: Music from the heart, the soul and the Church".

Sir Elton added, on Instagram: "Her voice was unique, her piano playing underrated — she was one of my favourite pianists. I was fortunate enough to spend time with her and witness her last performance — a benefit for the Elton John Aids Foundation at St John The Divine Cathedral.

"She was obviously unwell, and I wasn't sure she could perform. But Aretha did and she raised the roof. She sang and played magnificently, and we all wept. We were witnessing the greatest soul artist of all time. I adored her and worshipped her talent. God bless her.

"My condolences to all her family and friends. We shared the same birthday — and that meant so much to me. The whole world will miss her but will always rejoice in her remarkable legacy. The Queen is dead. Long live the Queen."

Former US president Bill Clinton paid tribute to "one of America's greatest national treasures".

He said in a statement: "I'll always be grateful for her kindness and support. She will forever be the Queen of Soul and so much more to all who knew her."

Aretha Franklin belting out hits in 2007 and (inset right) 2012

TV's Stacey Dooley set to join Strictly

BY ANDREW ARTHUR

JOURNALIST and documentary presenter Stacey Dooley is the eighth celebrity contestant confirmed for the brand new series of Strictly Come Dancing.

The announcement was made on the BBC dancing competition's social media channels.

Dooley said: "It's happening!

"I'm taking part in Strictly Come Dancing this year and my mother is going to explode."

The journalist joins the already announced line-up of celebrities including This Morning's Dr Ranj Singh, former cricketer Graeme Swann, television presenter Katie Piper, Steps singer Faye Tozer, Red Dwarf actor Danny John-Jules, YouTube star Joe Sugg and DJ Vick Hope.

Appendix C

NB: Identifiable information and logos have been removed from this document

Title of Project: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer

What is the research study about? When a parent has advanced cancer this presents the family with many challenges including communicating with the children. While much is known about how healthcare professionals tell adult patients that their illness is life threatening much, less is known about how healthcare professionals support parents with advanced cancer to communicate this difficult news with their children. We would like you to take part in a one to one face to face interview. The purpose of which is to explore your lived experience and support needs as you prepare your children for the diagnosis received by you or your partner.

Why you have been chosen? You have been chosen as you have a diagnosis of advanced cancer and have dependent children aged 18 and under. We acknowledge this is a difficult time for you and your family and greatly appreciate your interest.

Why should you consider taking part? By participating in the face to face interviews you will help us further explore the support needs of parents as they prepare their children for the death of a parent.

What will taking part involve? You are invited to take part in one to one interview, lasting approximately 60 minutes. You will not have to answer any questions you do not want to. The face to face interview will be conducted by an experienced researcher and will be digitally recorded. It is entirely up to you whether or not to take part.

Will people be able to identify you from this study? Everything you tell us will be treated with strict confidence (nobody apart from the research team will be able to access the data).

Where will the information be stored? Digital recordings will be kept in a locked secure cabinet at Ulster University, which only the research team will have access to. Transcribed data will be stored on a password protected computer belonging to Ulster University. Once the study is complete all personal and/or identifiable information will be destroyed in accordance with research protocol.

Is there any risk involved in taking part in the research? It is important for you to know that if you disclose any psychological or emotional concerns during the interview, the interview

will be stopped. The interview will only continue when and if you are happy to proceed. If required, we can speak to or you will be sign-posted to available counselling services and advised to speak to your main healthcare provider.

What happens if I want to withdraw from the study? If you decide to withdraw from the study either during or after the interview you do not have to give a reason, we will however, ask for your consent to be able **to use the data collected.** Again, you do not have to consent to this if you do not wish to. If you decide to withdraw during or after the interview and don't want us to retain any of your data, all the data we have collected from you will be destroyed and your decision will still be respected. You should be aware that once the interview transcripts have undergone analysis it will be no longer possible to separate your information as it will be unidentifiable. Your participation or non-participation will not affect your healthcare in anyway.

Will my information be kept confidential? Yes. All information you share during the interviews will be treated in the strictest confidence and none of your details will be shared with anyone other than members of the research team. Your information will be anonymised and securely kept in lockable drawers and on a password-protected computer with access restricted to the research team only. All information will be handled and stored in accordance with the requirements of the Data Protection Act 1998 and any anonymised data we have stored will be destroyed after ten years in line with our University policy. It is important for you to know that in the unlikely event of you telling us something that would make us worry about your safety or the safety of someone else we will need to pass this information on to, or direct you to the appropriate healthcare professionals (known to you) or the appropriate counselling services for you.

What happens if something goes wrong? This research has received ethical approval from Ulster University, South West - Cornwall & Plymouth Research Ethics Committee and research governance approval from XXXXX. It is very unlikely that anything will go wrong. The Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at

http://research.ulster.ac.uk/rg/0208ResearchVolunteerComplaintsProcedure.pdf

If you wish to make a complaint you can also contact the Research Team as detailed at the end of this Information Sheet or Mr Nick Curry, Head of Research Governance, Ulster University Tel: 02890 366629

What happens after the study finishes? The study will take approximately 12 months. We will then publish and present the findings as widely as we can and we will try our best to make sure that everyone who has taken part will have access to the results.

What do I do now? Thank you for taking time to read this Information Sheet. If you have any further questions about the study, please do not hesitate to contact one of the researchers named below.

If you are willing to participate in the interview, contact Jeffrey Hanna whose details are below.

Contact Details

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Appendix D

NB: Identifiable information and logos have been removed from this document

Title of Project: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer

What is the research study about? When a parent has advanced cancer this presents the family with many challenges including communicating with the children. While much is known about how healthcare professionals tell adult patients that their illness is life threatening much less is known about how healthcare professionals support parents with advanced cancer to communicate this difficult news with their children. We would like you to take part in a one to one face to face interview. The purpose of which is to explore your lived experience and support needs as a bereaved parent or a significant adult who prepared dependent children for the death of their parent.

Why you have been chosen? You have been chosen as you are a parent, guardian or a significant adult (i.e. someone who had a legal caring responsibility for dependent children e.g. grandparent or aunt) who has prepared dependent children, aged 18 years and under for the death of their parent.

Why should you consider taking part? By participating in the face to face interviews you will help us further explore the support needs of parents, guardians or significant adults as they prepare dependent children for the death of a parent.

What will taking part involve? You are invited to take part in one to one interview, lasting approximately 60 minutes. You will not have to answer any questions you do not want to. The face to face interview will be conducted by an experienced researcher and will be digitally recorded. It is entirely up to you whether or not to take part.

Will people be able to identify you from this study? Everything you tell us will be treated with strict confidence (nobody apart from the research team will be able to access the data).

Where will the information be stored? Digital recordings will be kept in a locked secure cabinet at Ulster University, which only the research team will have access to. Transcribed data will be stored on a password protected computer belonging to Ulster University. Once the study is complete all personal and/or identifiable information will be destroyed in accordance with research protocol.

Is there any risk involved in taking part in the research: It is important for you to know that if you disclose any psychological or emotional concerns during the interview the interview will be stopped. The interview will only continue when and if you are happy to proceed. If required, we can speak to or you will be sign-posted to available counselling services and advised to speak to your main healthcare provider.

What happens if I want to withdraw from the study? If you decide to withdraw from the study either during or after the interview you do not have to give a reason. We will however, ask for your consent to be able to **use the data collected**. Again, you do not have to consent to this if you do not wish to. If you decide to withdraw during or after the interview and don't want us to retain any of your data, all the data we have collected from you will be destroyed and your decision will still be respected. You should be aware that once the interview transcripts have undergone analysis it will be no longer possible to separate your information as it will be unidentifiable. Your participation or non-participation will not affect your healthcare in anyway.

Will my information be kept confidential? Yes. All information you share during the interviews will be treated in the strictest confidence and none of your details will be shared with anyone other than members of the research team. Your information will be anonymised and securely kept in lockable drawers and on a password-protected computer with access restricted to the research team only. All information will be handled and stored in accordance with the requirements of the Data Protection Act 1998 and any anonymised data we have stored will be destroyed after ten years in line with our University policy. It is important for you to know that in the unlikely event of you telling us something that would make us worry about your safety or the safety of someone else we will need to pass this information on to, or direct you to the appropriate healthcare professionals (known to you) or the appropriate counselling services for you.

What happens if something goes wrong? This research has received ethical approval from Ulster University, South West - Cornwall & Plymouth Research Ethics Committee & research governance approval from XXXXXX. It is very unlikely that anything will go wrong. The Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at http://research.ulster.ac.uk/rg/0208ResearchVolunteerComplaintsProcedure.pdf

If you wish to make a complaint you can also contact the Research Team as detailed at the end of this Information Sheet or Mr Nick Curry, Head of Research Governance, Ulster University Tel: 02890 366629

What happens after the study finishes? The study will take approximately 12 months. We will then publish and present the findings as widely as we can and we will try our best to make sure that everyone who has taken part will have access to the results.

What do I do now? Thank you for taking time to read this Information Sheet. If you have any further questions about the study, please do not hesitate to contact one of the researchers named below.

If you are willing to participate in the interview, contact Jeffrey Hanna whose details are below.

Contact Details

Dr Cherith Semple
Reader in Clinical Cancer Nursing
Ulster Hospital
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Professor Eilis McCaughan
Chief Investigator
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Appendix E

NB: Identifiable information and logos have been removed from this document

Date

Dear

We are contacting you regarding a study being conducted by Ulster University, Institute of Nursing and Health Research by Prof Eilis McCaughan and her team.

As an organisation, (organisation name) are interested in supporting research which may help to better understand and find ways of improving care for patients and their families.

The research team are interested in your perspective and we are contacting some people known in the past or who are currently known to (organisation name) to let them know about the research in case they may be interested in learning more.

We have enclosed some information from the research team at Ulster University which will give you more information. It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with (organisation name).

If you are interested in learning more about this study, please review the enclosed information from Ulster University and get in touch with the research team. We have NOT provided the research team with your contact details, so if you are not interested in the study you will not be contacted again.

Many thanks for your support

XXXXXXXXXXX

Appendix F

NB: Identifiable information and logos have been removed from this document

Title of Project: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer

What is the research study about? Effective communication with healthcare professionals is a high priority for patients and their families, especially for those diagnosed with a life-threatening illness such as cancer. Parents have a desire and need for support from frontline oncology staff to communicate their diagnosis with the children and manage the far reaching implications of parental cancer.

We would like you to take part in a one to one face to face interview. The purpose of which is to explore your views and attitudes on providing care for families when a parent has advanced cancer and how best to facilitate open family communication and provide the necessary support. We would also like to explore your perceived knowledge and confidence when providing parents with the support on preparing children for the death of a parent with cancer, and what training needs you think are required.

Why you have been chosen? You have been chosen as you currently work within an NHS setting and your caseload includes patients who are diagnosed with advanced cancer and who have children.

Why should you consider taking part? By participating in the interviews, we will explore your views on how best to empower parents to support and prepare their children for the death of a parent with cancer.

What will taking part involve? Face to face interviews will last approximately 30 minutes. Nothing we will ask will be too personal or embarrassing and, of course, you will not have to answer any questions you do not want to. The face to face interview will be conducted by an experienced researcher and be digitally recorded. It is entirely up to you whether or not to take part.

Will people be able to identify you from this study? Everything you tell us will be treated with strict confidence (nobody apart from the research team will be able to access the data).

Where will the information be stored? Digital recordings will be kept in a locked secure cabinet at the Ulster University, which only the research team will have access to. Transcribed

data will be stored on a password protected computer belonging to Ulster University. Once the study is complete all the information will be destroyed in accordance with research protocol.

Is there any risk involved in taking part in the research? It is important for you to know that in the unlikely event of you telling us something that would make us worry about your safety or the safety of someone else we will make sure that we pass on this information to those who need to know. If you have any concerns or worries about what we are asking you to do you can contact one of the researchers whose contact details are given at the bottom of this Information Sheet.

What happens if something goes wrong? This research has received ethical approval from Ulster University, the Office of Research Ethics Committee Northern Ireland (ORECNI) and research governance from this NHS trust. It is very unlikely that anything will go wrong. The Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at http://research.ulster.ac.uk/rg/0208ResearchVolunteerComplaintsProcedure.pdf .

If you wish to make a complaint you can also contact the Chief Investigator, whose details are at the end of this Information Sheet.

What happens after the study finishes? The study will take approximately 12 months. We will then publish and present the findings as widely as we can and we will try our best to make sure that everyone who has taken part will have access to the results.

What do I do now? Thank you for taking time to read this Information Sheet. If you have any further questions about the study, please do not hesitate to contact one of the researcher named below.

If you are willing to participate in the study let your manager know or contact Jeffrey Hanna, whose details are below.

Contact Details

Dr Cherith Semple
Reader in Clinical Cancer Nursing
Ulster Hospital
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Professor Eilis McCaughan
Chief Investigator
Professor in Cancer Care
Institute of Nursing and Health Research
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Appendix G

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Title of Project: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer

What is the research study about? Effective communication with healthcare professionals is a high priority for patients and their families, especially for those diagnosed with a life-threatening illness such as cancer. Parents have a desire and need for support from frontline oncology staff to communicate their diagnosis with the children and manage the far reaching implications of parental cancer.

We would like you to take part in a one to one face to face interview. The purpose of which is to explore your professional experience and involvement in working with families when a parent has advanced cancer and are at end of life. We would also like to explore your perceived knowledge and confidence when providing parents with the support on preparing children for the death of a parent with cancer. This may include support you are providing the family after that parent has died and what training needs you think are required.

Why you have been chosen? You have been chosen as your line of work has direct involvement with these families when a parent of dependent children is at end of life.

Why should you consider taking part? By participating in the interviews, we will explore your views on how best to empower parents to support and prepare their children for the death of a parent with cancer.

What will taking part involve? Face to face interviews will last approximately 30 minutes. Nothing we will ask will be too personal or embarrassing and, of course, you will not have to answer any questions you do not want to. The face to face interview will be conducted by an experienced researcher and be digitally recorded. It is entirely up to you whether or not to take part.

Will people be able to identify you from this study? Everything you tell us will be treated with strict confidentiality (nobody apart from the research team will be able to access the data).

Where will the information be stored? Digital recordings will be kept in a locked secure cabinet at Ulster University, which only the research team will have access to. Transcribed data

will be stored on a password protected computer belonging to Ulster University. Once the study is complete all personal and/or identifiable information will be destroyed in accordance with research protocol.

Is there any risk involved in taking part in the research? It is important for you to know that in the unlikely event of you telling us something that would make us worry about your safety or the safety of someone else we will make sure that we pass on this information to those who need to know. If you have any concerns or worries about what we are asking you to do you can contact one of the researchers whose contact details are given at the bottom of this Information Sheet.

What happens if something goes wrong? This research has received ethical approval from Ulster University and South West - Cornwall & Plymouth Research Ethics Committee. It is very unlikely that anything will go wrong. The Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at the following link:

http://research.ulster.ac.uk/rg/0208ResearchVolunteerComplaintsProcedure.pdf

If you wish to make a complaint you can also contact the Research Team as detailed at the end of this Information Sheet or Mr Nick Curry, Head of Research Governance, Ulster University Tel: 02890 366629

If you wish to make a complaint you can also contact the Chief Investigator, whose details are at the end of this Information Sheet.

What happens after the study finishes? The study will take approximately 12 months. We will then publish and present the findings as widely as we can and we will try our best to make sure that everyone who has taken part will have access to the results.

What do I do now? Thank you for taking time to read this Information Sheet. If you have any further questions about the study, please do not hesitate to contact one of the researcher named below.

If you are willing to participate in the study let your manager know or contact Jeffrey Hanna, whose details are below.

Contact Details

Dr Cherith Semple
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Appendix H

Initial topic guide for interviews with parents at EOL

1. **Sharing initial cancer diagnosis**

2. Prognosis is poor - no longer curative but advanced cancer

Hearing the news

- Concerns and feeling surrounding the children

Coming to terms with a poor prognosis

- How does this impact what the children know about your concern?

Telling the children

- What was shared with the children?
- Why was it important to communicate with the children?
- What were the words (language used - die) (developmental ages)?

- How best (where)?
- Who told the children?
- Were the children together / separate?
- Were you worried about questions the children might ask? If so, what questions?

3. Emotions / reactions to the news of advanced cancer

- How did it feel telling the children?
- Did you talk through it with anyone else?
- Any particular difficulties / barriers / challenges

Childrens' reactions / understanding?

What has changed?

Family dynamics: balancing the needs of family members

Support needs:

Emotional - do you talk about how you're feeling to others to include the children?
Financial - plans that might need to be considered
Practical - day-to-day things that need done

Who helps? What support do they provide? How helpful is it?
What else would be beneficial to help you prepare for end of life? (unmet support needs)

Children's needs - emotional / practical etc

4. Preparing to say goodbye

How? Quality time?
Creating memories?
Why is this important?
Any support with this from anyone / anything that might help?

<u>Death is close</u>

- What do you think the children need to know and/or understand as the end comes very close?
- How are you / have you talked to the children about this?
- Views on the children seeing you when you are in the final moments of life?

- What about just after?

- What about the funeral?
- What preparations do you think are important to help the children cope after your death?

5. Anything else we haven't covered that you consider important

Appendix I

Initial topic guide for interviews with bereaved parents

1. **As parents, how did you tell the children that X was no longer going survive his /her cancer?**

Prompts:

- Emotional readiness to share the news
- Decision making process as parents to tell the children / conflicting views
- Preparation/ need for guidance – seek advice or support (if so, for what, why)
- Concerns and feelings surrounding telling the children
- Actual telling the children (what was shared, who told them, were they together)
- Children's reactions / desire for information
- Parent's reflections on telling

2. **As a family, how did you prepare the children to say goodbye to X?**

Prompts:

- Creating memories / spending time together
- What was helpful for the 1) children 2) X (parent with cancer) and 3) yourself when preparing to say goodbye

3. **How did you prepare the children for the actual death / final moments of life?**

Prompts:

- Children's understanding, reaction, worries, concerns, questions about the death of their Mum / Dad
- Support or help with preparing the children for the actual death
- Description of the event

4. **As a family, how did you manage the funeral period?**

Prompts:

- Seeing the body
- Attending the funeral - preparation
- What helped the children cope at this time

5. **What support did you as a family require / find helpful?**

(When death was imminent, surrounding the funeral, after the funeral)

Prompts:

- emotional, practical, financial
- from family /outside the family
- unmet needs - was there anything or support that could have made this period less challenging

6. **How would you describe family life since the death of X?**
    a. What has changed?
    b. How have the children coped? (behavioural changes, school performance)
    c. What has helped? i) the children & ii) you as a parent

Appendix J

Sample updated topic guide for interviews with bereaved parents

<u>Into – their story (Brief)</u>

1. **Start with: contemplating / planning to tell the children about poor prognosis (not going to survive his /her cancer)**

2. **Life at this time for the family : Life between prognosis received and end of life**

Prompts:

- What was the key focus regarding family life at this time?
- Any preparation with the children for parent not going to be there (Finances / wills)?
- The needs of the well-parent (now bereaved parent) and ill-parent . Financial needs?
- Where the kid(s) asking questions? If so, what? How were these addressed?
- Who was around to provide support? - Family, Friends, neighbours, church involvement?
- Any conversations between parents/or with children surrounding the death and, or the future?
- Where parents looking for something / someone to help prepare the children for the death of their Mum or Dad? If so, what?
- What would have been helpful?
- Additional reflections on how this period was regarding

3. **Role of the HC teams - supporting their family when a parent is dying**

4. **As parents, how did you tell the children that X was no longer going survive his /her cancer?**

    - Emotional readiness to share the news
    - Decision making process as parents to tell the children (conflicting views)
    - Need for guidance – seek advice or support (if so, for what, why)
    - Concerns and feelings surrounding telling the children
    - Actual telling the children (what was shared, who told them, were they together)
    - Children's reactions / desire for information

- Bereaved parent's reflections on telling

5. How did you prepare the children for the actual death / final moments of life?

Prompts:

- Children's understanding, reaction, worries, concerns, questions about the death of their Mum / Dad
- The role of the hospice, if applicable
- **Where the kids present for dying?**
- **Support or help with preparing the children for the actual death**
- Description of the event

6. Navigating the immediate bereavement period

Prompts:

- Seeing the body
- Attending the funeral - preparation
- What helped the children cope at this time
- Any funeral director involvement, or what was supportive?
- Anything that could have made this period less challenging

5. How would you describe family life since the death of X?

a. What has changed?
b. How have the children coped? (behavioural changes, school performance)
c. What has helped? i) the children & ii) you as a parent

6. Key nuggets

- Advice to another parent in similar situation.
- Would you have done anything differently? Reflections
- What would have helped?

Appendix K

Initial topic guide for interviews with HSCPs

1. What are parents doing when they have an poor cancer prognosis?

Prompts: *What are they sharing with their children?*
Walk me through what that journey looks like. How does it change?
What are families (parents + children) experiencing throughout?
How does that journey change? Differing needs at different times.
Complexities with advanced cancer/EOL?

2. Current practice: tell me a little of your experience of caring for parents with young children who are dying from cancer

Prompts: Why have you engaged/ is it part of your routine/ do you think it should be
What do they see from a parenting perspective that challenges them
Issues specifically for children
Families with complex needs
If parents need to know something about supporting their child… what is it?

3. What is/has been your role in facilitating that support

Prompts: What is your role as a HSCP
What do you believe you should be doing
Is it something that should be part of your care
Is it part of your routine? Do you think it should be?

4. Within your role how do you think you could best equip these parents at the end of life

Prompts: How can we equip and support you as a HCP
What key content would equip you so you feel empowered to support parents at the end of life

5. Anything else relevant not considered

Appendix L

Initial topic guide for interviews with funeral directors

- **To hear what is their experience and involvement with younger families when a parent has died**
  - Frequency of these
  - What role are they playing?
  - What do these parents struggle with during the immediate bereavement? What is it parents are looking for, if anything?
  - What nuggets of advice are they giving in preparing for the body, funeral, cremation etc. - language and words
  - How does the funeral director prepare the parent for the funeral? Again, the nuggets of what they are doing in reality.

- **Has the funeral director had any training surrounding best practice for children & death?**

- **Generational change?**
  - How is death described? words & language?
  - Death as a taboo?

- **Are funeral directors signposting to support services? What do they know is available?**

- **Do funeral directors have books + resources that they are giving to families? What are they and where did they get them?**

- **Differences if mother or father dies? Is there differences in what a male or female parent need? How do they manage? Gender differences**

- **Are younger families making contact before the funeral to make arrangements? Are they contacting on social media/email?**

- **Have any families come back after the funeral to speak with the F.D? Why? For what?**

- **What is unique/different for these families compared to when an older person would die?**

Appendix M

Title of Project: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer

Consent Form

1. I confirm that I have read and understand the Information Sheet (dated 18/09/2018) for the above study. I have had the opportunity to consider the information and ask questions.	
2. I understand that any participation is voluntary and that I can choose to withdraw at any time during or after this interview without giving any reason and without affecting my legal rights.	
3. I understand that if I withdraw from the study, either during or after the interview, any information gathered prior to me withdrawing may be used.	
4. I understand that all the information provided by me will be stored confidentially at the Ulster University and that I will not be identifiable in any data published in relation to this project.	
5. I am willing to participate in an interview.	
6. I understand the interview with a member of the research team will be recorded.	
7. I consent to direct quotes I make being anonymously used in subsequent reports and publications	
8. I am willing to participate in the above named study.	

Please tick and initial each box to show your agreement with the following:

Name (printed)	Signature	Date (dd/mm/yy)
Researcher name (printed)	Signature	Date (dd/mm/yy)

Appendix N

Appendix O

Sample interview reflection 01

At a general level, I felt this was quite a challenging interview for two reasons. The first was a lack of reflection over what had been done and second not remembering details, perhaps due to an emotional blank. As a result, when issues were attempted to be explored further, there was an inability to do so as the answer was 'I don't remember or I don't know'. The concept of emotional readiness was evident between the two parents. Even when HPs informed that the prognosis and outcome was poor, both parents still had the belief and hope that the parent was going to be heal because of their faith. As a direct consequence, the children were not prepared for the death of their parent, and neither were the parents themselves, despite the declining health at the time.

One factor that became very evident to me in the interview was the two separate relationships in this family. One relationship being the husband and wife and the second being the relationship with the children. From my perspective, there was no merging of the two. This was clear in that the children were very much kept in dark over the parent's ill health at the time, a lack of open communication, and visiting the parent in hospital. The negative impact of all of this is evident now when the oldest daughter is displaying signs of anxiety, withdrawal symptoms and regret in not being able to spend time with her father, particularly during the prolonged period, while he was in hospital.

It was a challenging interview to explore what the specific support needs were and what was most supportive during that time. What I did however note was the lack of support from anyone when the parent was ill. There was a lack of visitors (initially), there was no friends nearby - I got the real sense that the healthy parent was batting this on her own and with her kids being kept in the dark, she had no one to share this journey with.

The parent was quite firm in her beliefs that she had made the right choices at certain times, for example, she believes she was right in not letting her children go to the hospital. The parent was almost seeking for validation at certain times and as a researcher, particularly for Cherith, this is challenging as we are not there to cause any further harm or upset but rather to accept their views as such and move on.

In terms of grief for the children, the parent was strongly encouraging and desiring for tears and anger from the kids; however, that was not happening and I am presuming because the children had no idea what they were grieving for as they were unprepared for this.

When her husband was in ICU, the only time she could visit her husband was the morning, however with visiting being afternoon and evening, this meant that she was not allowed to visit him as she had to be at home for her children. A lot of anger and resentment was made to the fact she could not visit her husband. She made the case that the children needed the well parent (being herself) despite the fact the ill parent was in hospital.

Sample interview reflection 02

- It has become more evident that there is a huge benefit to interviewing the bereaved parent in addition to the end of life parent. There are elements that are being addressed that would not be explored in end of life parent interviews. Consistently, emotional readiness is a contributing factor in the end of life parent to have these conversations and it is the healthy parent who wants to avail of support and tell the children. Alike other interviews, this bereaved parent acknowledged how she will have the long-term care of the children after the parent has died and therefore needs and wants to best support their children and receive help and support in having these conversations.

- The support from Cancer Focus and attending the bereavement support group was acknowledged in this interview. There is that sense that attending this group provides the bereaved parent with peer support in knowing that they are not alone and others are out there who have/are experiencing the same as them and they are not the only one exposed to this. Having a supportive peer network is a powerful source of support for the bereaved parent.

- Subtly, there appeared to be a sense of anger from the bereaved parent. This was in response to finding it difficult to manage/cope with the kids. There was a sense of resentment towards those kids as this was not how they (both parents) had planned their life to be and now the bereaved parent is being left with the kids.

- Crucially, there is a need for healthcare professionals to provide a more realistic timeline. In this interview it fueled towards emotional readiness and holding off in the telling the kids about the father's cancer and dying. Within this, there was a clear lack of support and guidance in relation to the illness; how advanced the cancer was; a lack of health professional input in talking to the children and preparing for what was ahead.

- In addition to the delay in telling the children, this was fueled by the painful impact of 'going there' to have these conversations. In particular, the dying parent was holding on to positive

hope and putting his energy into fighting the disease (despite being spread to lymph nodes, brain etc) and not addressing the issues until there was no further avenues or course of treatments to explore. The dying parent appeared to be in denial of what was happening and hoping for a cure and that treatment may prolong life. Even then, the dying parent did not want to know information such as 'how long' and these questions were only addressed when the bereaved parent approached healthcare professionals alone. The bereaved parent bought a notebook for the dying parent to write letters/create memories for the children, to which the dying parent did not do (perhaps due to the emotional difficulty of doing so or thinking there was more time to so). As a result, it's very much the bereaved parent in the driving seat and navigating decisions during this difficult time.

- In addition to the lack of a clear timeline/understanding of the illness from healthcare professionals and the dying parent holding on to hope, these can be collectively branched under the theme of a lack of preparation. Despite influences and opportunities being presented to the dying parent, such as two visits from the minister to make funeral arrangements, the dying parent still did not want to go there. There is that sense that the dying parent is not preparing themselves for what is ahead.

- One of the challenges in these interviews is to gain a complete picture of what the specific support needs are of these families. While this bereaved parent did talk about the amazing support she received from Rachel/Cancer Focus, when asked what that support was specifically, the answer was 'I don't know' - a level of 'fuzziness'. As a result, these are not sharp reflections. The positive side to this is that as these parents are identified from Cancer Focus, Rachel will hopefully be able to identify to us what it is these parents need, if we cannot obtain this in subsequent interviews. Additionally, this is something I would like to explore at the family nights and identify what concerns/questions are addressed from parents then. Furthermore, it is worthwhile to acknowledge one area where the bereaved parent felt support was when knowledge and reassurance was provided, for example, understanding that not all children may cry.

- A further issue arising is the idea that these parents think they have been 'cheated by death'. Bar one interview, these parents report how they cling onto hope that they may have extended time with their partner (e.g. up to a year) but in reality they only get up to 3 months. Again, a factor which can contribute towards a lack of preparation. This is an avenue to explore in subsequent interviews and whether these parents believe they have been 'cheated by death'

- As reflected in previous interviews, the concept of one size fits all is a challenge, as the uniqueness of each family contributes and impacts how a parent may cope/manage this time. That is, there are so many factors and variables happening in each family that come into play that may impact their open communication with their children. For example, the educational level of the bereaved/dying parent (i.e. the knowledge and insight they have may influence their preparations), financial constraints etc. Within this interview, the family dynamic was quite clear that the dying parent was the breadwinner and the bereaved parent took responsibility for the parenting, however, the bereaved parent was not involved/included in consultations. This uniqueness strongly contributes towards Family Centered Cancer Care in that it is important to have that sense of who is in the family and to ensure the appropriate family members are involved and included. The bereaved parent reported those feelings of isolation and exclusion and felt very unsupported from health professionals when her husband was actively dying.

Sample interview reflection 03

Like the previous, my mindset for this interview was to explore from the healthcare professional (HCP) the 'journey' for families from the moment a parent's cancer has become advanced/ palliative/terminal, what parents are sharing with their children throughout the cancer trajectory etc. This HCP suggested in their experience parents are open to telling their children and managing that situation themselves, to the extent they have never been asked for advice and support. Similarly, while parents where suggested to not have asked for advice and support, the HCP suggested they do not initiative conversations about the children.

However, while trying to explore what the journey looked like for the family, I uncovered some of the following:

- Families, particularly the parents are dealing with uncertainty. This is fueled by stress and anxiety over the illness trajectory and the (non) successes and of treatments. The HCP suggested families are attempting to manage this by spending time together and making the best of the time they have: 'taking each day as it comes and living in the moment as much as possible'. Spending time together was also suggested to be captured through taking pictures and videos together.
- 'Treatment is not so black and white and things are not so linear'. This is similar to the concept of uncertainty. At periods the parent is living relatively well and others quite ill. 'It's up and down and it's continuously changing'. But, when death is becoming more imminent, parents often think the ill-parent is having a 'down spell' and will recover like previous times

when they were quite poorly. The HCP used the term ‘denial’ here to explain this response at this juncture. This was perceived to be a potential blockage to telling the children the reality of the situation.

- Parents are in a period of denial for ‘potentially quite some time’ when they have been given a diagnosis that is palliative/terminal/end of life/ advanced. The HCP suggested this is a typical process and they require time (varies on each individual as to how long) to come to a greater level of ‘acceptance’. Acceptance in this context was referred to as understanding they are going to die from their illness.
- Parents are often focused on a message of hope. Hope that treatments will help them live longer. It was suggested sometimes in these instances parents are not ‘completely open with their children’.
- Parents anger at the situation was also identified as a perceived blockage. It was suggested as a consequence of the anger, parents do not want to inform their children as they don’t want ‘to put unnecessary emotions on their children’. The HCP felt their role here was ‘to listen to their concerns and reassure them that it’s not wrong to feel that way’.

In terms of informational support/advice/guidance, this HCP felt they were limited as to what they could provide. They felt it was ‘too niche of an area and required more specialist input and involvement’, such as a child psychologist. They felt the best support they could provide was to manage symptoms (treating the primary problem).

Sample interview reflection 04

This interview was quite difficult to navigate at times. I felt in many instances they were quite unreflective were a typical response was ‘I don’t know’.

They suggested any conversations they have with parents regarding the children are relatively mundane - ‘where is the child today?’ ‘is he/she at school?’. They suggested they never have been asked any questions regarding preparing or sharing the news with the children. They also suggested parents are not looking advice and guidance from them. Also, they have not directly asked the parents do they need any advice/support/guidance etc. regarding the children. They also stated they hope they are not asked as they do not know how to advise. They also had no awareness of any of the charities that would be available to signpost too.

While initially a little unreflective, in attempts to explore from experiences and perceptions what is happening in family life the following was captured:

- The family want to maintain relative normality as best as possible, for as long as they can. However, this can be challenging as treatments are regularly changing. The HCP felt their role and priority was symptom management (treating the primary problem as opposed to advising how they could live relative normality).
- The period of well-functioning. As family life is functioning relatively normal, there may be limited direct preparations being made (having conversations and telling the children), but rather indirectly ensuring time is being spent together and creating memories for the future.
- Anger was identified as a perceived blockage to telling the children the reality of the situation.
- Parents delay telling the children (in some instances up until the final days) in their attempt to protect their children from upset and further harm. The HCP suggested they would encourage the parents to share the news with their children and 'to be open and honest', but only if the parent asked the HCP directly. It was further suggested that the HCP was never asked.
- Some parents were suggested to be struggling with child-care. In these families they were suggested to have a lack of supportive networks available. In one situation, the children were suggested to be missing school as the parent was unable to take them.
- Some families are struggling financially. In some cases, both parents have had to give up work. These families were suggested to manage this themselves. The HCP was unable to offer any guidance or advice.
- Denial was identified as potential blockage. Denial in this context was defined as not accepting the reality of the situation.

This HCP felt their role was to help manage symptoms. If they were asked specific questions or parents sought advice/guidance this HCP suggested they would directly signpost to the 'Cancer Centre for a specialist nurse to speak with them'

Sample interview reflection 05

This interviewee has been a funeral director since 1988 and acknowledged the increase in deaths in younger parents where there may be up to as many as 8-10 in one year.

When asked about change over time, this funeral director has suggested that more families now do not have church connections and more families want to conduct the service themselves.

In relation to the language around death, this funeral director suggested there has been a shift in this. In the 1980s he suggested people would have used the word 'died' and now people are saying 'passed-away'. To this end, the funeral director too acknowledged how he would use the term 'passed-away' too. Explore in future interviews.

With regards to children's involvement death and funerals, he acknowledged how sometimes parents want to keep them involved but sometimes the kids do not want to be there. This funeral director suggested 'if kids are involved in the end of life *journey* they cope better'.

At this time, parents are asking 'should we bring the coffin home? How will the kids cope with that?'. This funeral director continued by saying it depends on each family's situation… the term 'they know the kids best' was used here.

The funeral director suggested he prefers when the children are in the room when funeral arrangements are being made. In doing so, the funeral director suggested how it means they can be involved and have input into plans - they may wish to suggest a favourite song/hymn to be played. The funeral director suggested doing this puts the child's mind at ease because even if they are not directly having input, they are listening to the arrangements and have an awareness of what will follow over that immediate-bereavement period.

This funeral director acknowledged how families need **one** point of contact over the immediate-bereavement. He suggested that families who are using funeral directors who are part of the Co-op group are not getting the same service as independent run family funeral directors. This was suggested to be part due to no one point of contact in this group - where families are dealing with numerous people. Interviews are needed with these funeral directors to hear their perspectives.

When the funeral director was asked 'what key advice would you give these families?' his response was 'nobody knows your kids better than you do… always have 2-3 adults around who can be there to look after the kids and widowed parent - this is suggested to be helpful if one wishes to leave the service/graveyard - it gives choice to the other kids or the parent to stay or go.

The funeral director reported their sensitivity when arriving at the house for the first time. The importance for them to go in and speak with the family first as opposed to directly moving the body and leaving. Importance of that repour building and so it doesn't upset the children that the funeral director 'took Mummy/Daddy away'. In addition to this, the funeral director later suggested how this provides subtle ways to find out from parents what way the kids will react over the immediate bereavement period, which may be helpful for them in supporting the parent. In doing so, it also helps the funeral director to personalise any information-giving to the parent.

In relation to what words does the funeral director offer the parent to describe the dead body and coffin to the children no suggestions could be provided.

This funeral director suggested how for many of these young families it is the first time they are dealing with death and often they make contact before the death to find out information. This information was suggested to be 'who do I first contact if they die…what happens if they die over the weekend… how do I go about getting a grave… what happens to the body… what logistics are to be made' In short 'what is going to happen'.

With regards to the graveside and children - this funeral director suggested some do it and some don't. The funeral director suggested the importance to involve children as much as possible during the funeral, such as having the children walk alongside the coffin and put their hand on it if they can reach it. Giving the child a sense of importance and value.

This funeral director suggested there is a difference whether a mum or a dad dies. From recollection, I believe he suggested if a dad dies the kids want to remain close to the mum. This can relate to how children respond in other situations e.g. if they get hurt they go to mum first. Explore this further to see if other funeral directors find this.

In contrast to when a death happens to an older person, this funeral director suggested younger families are more inclined to have a closed coffin, more distressed and upset and younger children are likely to want to put a picture/note/card/keepsake in the coffin with the parent and want non-traditional funerals - blue/white/pink coffins.

In terms of training this funeral director suggested they have had no training and while they belong to the National Association of Funeral Directors he has 'never needed anything from them'. This is not what was suggested by the first funeral director and to be addressed in future interviews.

After the funeral, this funeral director suggested that families ***do not*** return following the funeral to speak with the funeral director and look for advice and guidance. Again - not what was suggested by the first funeral director. However, the funeral director suggested that he would 'ring a few days after the funeral and ask how are the kids getting on'.

This funeral director suggested he signposts families to Cruse Bereavement Care ***if they ask*** for any bereavement support advice.

Appendix P

NB: Identifiable information and logos have been removed from this document

Ulster University

Ulster University
Shore Road
Newtownabbey
County Antrim
BT37 0QB
Northern Ireland
T: +44 (0)28 9036 6552/6518/6629
ulster.ac.uk

Our Ref: NC:GOV

03 July 2017

Prof E McCaughan
Ulster University
School of Nursing
Coleraine Campus

Dear Prof McCaughan

SPONSORSHIP FOR PROJECT REFERENCE

Full Project Title: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer

Chief Investigator	Prof E McCaughan
Other investigators	Dr C Semple (SEHSCT)

I confirm that Ulster University will act as sponsor for the above research project as required by the Research Governance Framework for Health and Social Care.

This has been agreed with [redacted]

Please refer to the accompanying documentation for more information and to note the outline requirements placed upon investigators. In particular, you must seek appropriate ethical review and confirm that approval is in place before commencing the study.

Please do not hesitate to contact me should you require any further information.

Yours sincerely

Nick Curry
Head of Research Governance
028 9036 6629
n.curry@ulster.ac.uk

Appendix Q

NB: Identifiable information and logos have been removed from this document

NHS
Health Research Authority
South West - Cornwall & Plymouth Research Ethics Committee
Level 3
Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Tel: 0207 104 8041

15 June 2018

Professor Eilis McCaughan
Professor of cancer care
Ulster University
School of nursing
Coleraine campus, Cromore Road
Coleraine
BT521SA

Dear Professor McCaughan

Study title:	**Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer**
REC reference:	**17/SW/0155**
Amendment number:	**1**
Amendment date:	**20 April 2018**
IRAS project ID:	**224668**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee reviewed the following amendment (The changes involve phase 1 only (phase 2 and 3 are not affected by this amendment)):

a) Amendment to Information previously given in IRAS
1. Addition of two new sites - [redacted]
2. Addition of bereaved spouses (the surviving parent) to the inclusion criteria.
3. Extension of the study from 01/04/19 to 01/08/2021.
4. Recruitment of an additional 18 participants (or until data saturation occurs) therefore now a new total of n = 30 for Phase 1 A13 and A59. This will include both parents diagnosed with advanced cancer and bereaved (surviving) parents.
5. To place study advertisement - *researchers will ascertain their address and post/email.*

Appendix R

NB: Identifiable information and logos have been removed from this document

Study Ref:	02/18
Study title:	Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer
Chief Investigator:	Prof. Eilis McCaughan
Project Researcher:	Dr Cherith Semple/Mr Jeff Hanna
Local Collaborator:	[redacted]
REC Ref:	17/SW/0155
IRAS / CSP Ref:	224668
Research Site(s):	[redacted]

Dear Prof McCaughan,

Many thanks for forwarding on written confirmation of REC approval and associated documents on 13th August 2018. We are writing to confirm that the above research study has been granted Permission and can now be conducted at the hospice(s) listed above as a "Research Site(s)".

Permission has been granted on the basis of the study design described in the application form(s), protocol and related governance documentation. Study documents reviewed and approved included:

Document:	Version:	Date:	Details:
RESEARCH IMPACT ASSESSMENT FORM For all studies not processed through IRAS	1	01/05/18	Research Impact Assessment Form
RESEARCH DATA PROTECTION FORM For all studies not processed through IRAS	1	01/05/18	Research Data Protection Form

IRAS: Non-NHS SITE SPECIFIC INFORMATION FORM For all studies processed through IRAS	N/A	N/A	N/A
IRAS: REC/R&D FORM For all studies processed through IRAS		13/08/18	Original REC IRAS documentation Non-draft Amendment Form
ETHICS APPROVAL NHS/HRA or UNIVERSITY (PLEASE STATE) a) ~~Ulster University (attached)~~ b) IRAS – under review Aug 2016	N/A	N/A	Original REC Approval Letter (7th August, 2017) Confirmation of HRA REC Approval (9th August 2018)
OTHER REGULATORY APPROVAL i.e. MHRA, Confidentiality Approval Group (CAG), etc. (Give Details)	N/A	N/A	N/A
EVIDENCE OF SPONSORSHIP For IRAS studies this information is included in REC/R&D Form (SIGNED by Sponsor)	1	3rd July, 2017	Sponsorship Letter
EVIDENCE OF INDEMNITY For IRAS studies this information is included in REC/R&D Form (SIGNED by Sponsor)	1	3rd July, 2017	Statement of indemnity
FULL STUDY PROTOCOL Dated version approved by Ethics/Regulatory Committees	5	20th April, 2018	Appendix 1. Research Protocol
CONSENT FORM Dated version approved by Ethics/Regulatory Committees	N/A	N/A	Appendix 2. Participant Information Sheet – Advanced Cancer parents Interview and Consent (Version 7, 15/06/18) Appendix 11. Bereaved Participant information sheet (Version 3, 15/06/18)
PARTICIPANT INFORMATION SHEET Dated version approved by Ethics/Regulatory Committees	N/A	N/A	Appendix 2. Participant Information Sheet – Advanced Cancer parents Interview and Consent (Version 8, 15/06/18) Appendix 11. Bereaved Participant information sheet (Version 3, 15/06/18)

OTHER STUDY DOCUMENTS i.e. GP Letters, Questionnaires, etc. (GIVE DETAILS)	N/A	N/A	Appendix 14. Bereaved Support Pack (Version 3, 26/06/18) Appendix 13: Patient Support Pack (Version 2, 15/06/18) Appendix 7: Topic guide: Interview with parents (Version 1, 01/06/17) Appendix 10 Topic Guide bereaved parents (Version 1, 25/04/18) Appendix 8. Parents distress protocol (Version 2, 06/07/18) Appendix 5: Distress Protocol- Researchers (Version 2, 01/06/17)
RESEARCH TEAM CVs Including Chief and Principal Investigators	1	N/A	Eilis McCaughan Cherith Semple Jeff Hanna
RESEARCH TEAM GCP CERTIFICATES For CTIMP studies ONLY	1	June 2016 June 2016 October 2017	Eilis McCaughan Cherith Semple Jeff Hanna
CONTRACT / AGREEMENT Signed and Dated	N/A	N/A	N/A

You are also expected to conduct your study in accordance with the following:
You must adhere to the study design of the protocol at all times, except when research participants' health and safety is compromised. In such cases, you must take urgent and appropriate safety measures to ensure the protection of research participants, whilst immediately informing the Hospice Manager, Medical Director and Research Lead, as well any relevant Regulatory Bodies (i.e. Ethics / MHRA).

You are also expected to conduct your study in accordance with the following:

- Research Governance Framework: http://www.hra.nhs.uk/resources/research-legislation-and-governance/research-governance-frameworks/

- ICH Guidelines on Good Clinical Practice: http://www.ich.org/products/guidelines/efficacy/efficacy-single/article/good-clinical-practice.html
- Data Protection Act 1998: https://www.gov.uk/data-protection/the-data-protection-act
- All Applicable Policies and Procedures

It is also a stipulation of your permission that you provide the hospice with the following notifications / documents throughout the course of your study:

- Changes to start and / or end date
- Notification of any amendments to the research protocol and / or research team, including confirmation of approval from the appropriate regulatory body (i.e. Ethics / MHRA)
- Annual progress report, due 12 months after study commencement. Please use the *Hospice Research Annual Progress Report* template. For CTIMPS, HRA guidance is here: http://www.hra.nhs.uk/resources/during-and-after-your-study/progress-and-safety-reporting/
- End of study declaration, including confirmation from relevant regulatory bodies. Please use the *Hospice Research End of Study Notification* form. For CTIMPs, HRA guidance is here: http://www.hra.nhs.uk/resources/during-and-after-your-study/end-of-study-notification-clinical-trials-of-investigational-medicinal-products-ctimps-eudract-form/
- Final study report / results summary / conclusions.

You must also inform of us any **complaints** or **adverse events** in relation to the conduct of the research study.

We would like to take this opportunity to wish you well with your research. If you require any further advice, please do not hesitate to contact us.

Yours sincerely,

Research Governance Committee

Appendix S
Patient Support Pack

Marie Curie Support Line

To speak to helpline advisers for help and support for you and your family please contact the Marie Curie Support Line.

Website: https://www.mariecurie.org
Tel: 0800 716146.
Opening hours: Mon- Fri – 9am to 5pm and 11am-5pm Saturday.

Cancer Focus N.I. Family Support Service

The Cancer Focus NI Family Support Service helps families cope with the disruption to ordinary family life and minimises the long-term impact on children's emotional well-being when a mum, dad or close family member has cancer. Their Family Support worker will discuss your individual needs with you and will arrange whatever support is best for your family.

Website: https://cancerfocusni.org/patient-support/family-support/
Contact: Rachel Smith - Family support worker
Email: rachelsmith@cancerfocusni.org
Tel: 02890663281

Macmillan Cancer support

To speak to helpline advisors at Macmillan for advice and support call 08088080000 or visit www.macmillan.org.uk

Action Cancer

Action Cancer is Northern Ireland's leading, local cancer charity. Their mission is to save lives and support local people through cancer awareness, prevention, detection and support.

For information and support:
Website: http://www.actioncancer.org
Tel: 028 9080 3344

Support for any issues that may arise should also be sought in the first instance from your care provider, who can either provide in-house support or onward referral as appropriate.

Complaints about the Research

If you are not satisfied with the manner in which this study was conducted, or if you have any concerns, complaints, or general questions about the research as a research participant, please contact Professor Eilis McCaughan

Tel: 028 70124091

Email: em.mccaughan@ulster.ac.uk

If you wish to speak to someone other than a member of the research team, or if you cannot reach the research team, please contact Mr. Nick Curry, who is an informed individual and not a member of the research team.

Tel: 028 90 36 6629

Email: n.curry@ulster.ac.uk

Post: Room 26A17, Research & Innovation, Ulster University, Jordanstown Campus, Shore

Appendix T

Support Pack

Cruse Bereavement Care

Cruse Bereavement Care is a leading national charity for bereaved people in Northern Ireland. They offer support, advice and information to children, young people and adults when someone close to them dies. Cruse offers face-to-face, telephone, email and website support and is located in seven areas throughout Northern Ireland.

For more information:
Website: http://www.cruse.org.uk/
Tel: 0808 8081677.
Email: helpline@cruse.org.uk

Marie Curie Support Line

If you have lost a loved one cared for by Marie Curie Services and have been affected by any of the sensitive issues discussed during the interview and feel you need bereavement support, please contact the Hospice and we will arrange this support for you.

Contact: Helen Boal - Bereavement Co-ordinator
Tel: 02890882000

Cancer Focus N.I. Family Support Service

The Cancer Focus NI Family Support Service helps families cope with the disruption to ordinary family life and minimises the long-term impact on children's emotional well-being when a mum, dad or close family member has cancer. Their Family Support worker will discuss your individual needs with you and will arrange whatever support is best for your family.

Website: https://cancerfocusni.org/patient-support/family-support/
Contact: Rachel Smith - Family support worker
Email: rachelsmith@cancerfocusni.org
Tel: 02890663281

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For information and support:

Website: http://www.actioncancer.org

Tel: 028 9080 3344

Email: info@actioncancer.org

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Tel: 028 90 36 6629

Email: n.curry@ulster.ac.uk

Post: Room 26A17, Research & Innovation, Ulster University, Jordanstown Campus, Shore Road, Newtownabbey, Co. Antrim, BT37 0QB.

Appendix U

Distress protocol

Title of Project: Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer**.**

There are no known physical risks associated with participating in this type of research; however, it is acknowledged that discussion of sensitive topics such as advanced cancer, death and communicating such with their children may cause distressing and emotional feelings for both parents and staff. In the event that a participant becomes distressed, the following actions will be taken:

Privacy
The researcher will maintain privacy for the participant at all times.

Termination of the conversation
If the researcher becomes aware that a participant is becoming emotionally distressed, emotional or anxious they will stop the conversation. The participant will be reminded that they can change their mind and withdraw from the study and their decision will be respected.

For parents
The researcher will offer support from the senior nurse/counsellor (with the permission of the patient).

Alternatively, if the patient would like to talk to someone in (organisation name) who is not part of the nursing team looking after them, they will be advised that (organisation name) can provide a councillor or they can provide details of the support line which offers support and guidance.

Healthcare professionals
If the healthcare professional would like to talk to someone who is not part of the Trust they will be signposted to an independent source of support for staff, i.e. RCN, Unison, BMA etc. who can offer confidential support and guidance.

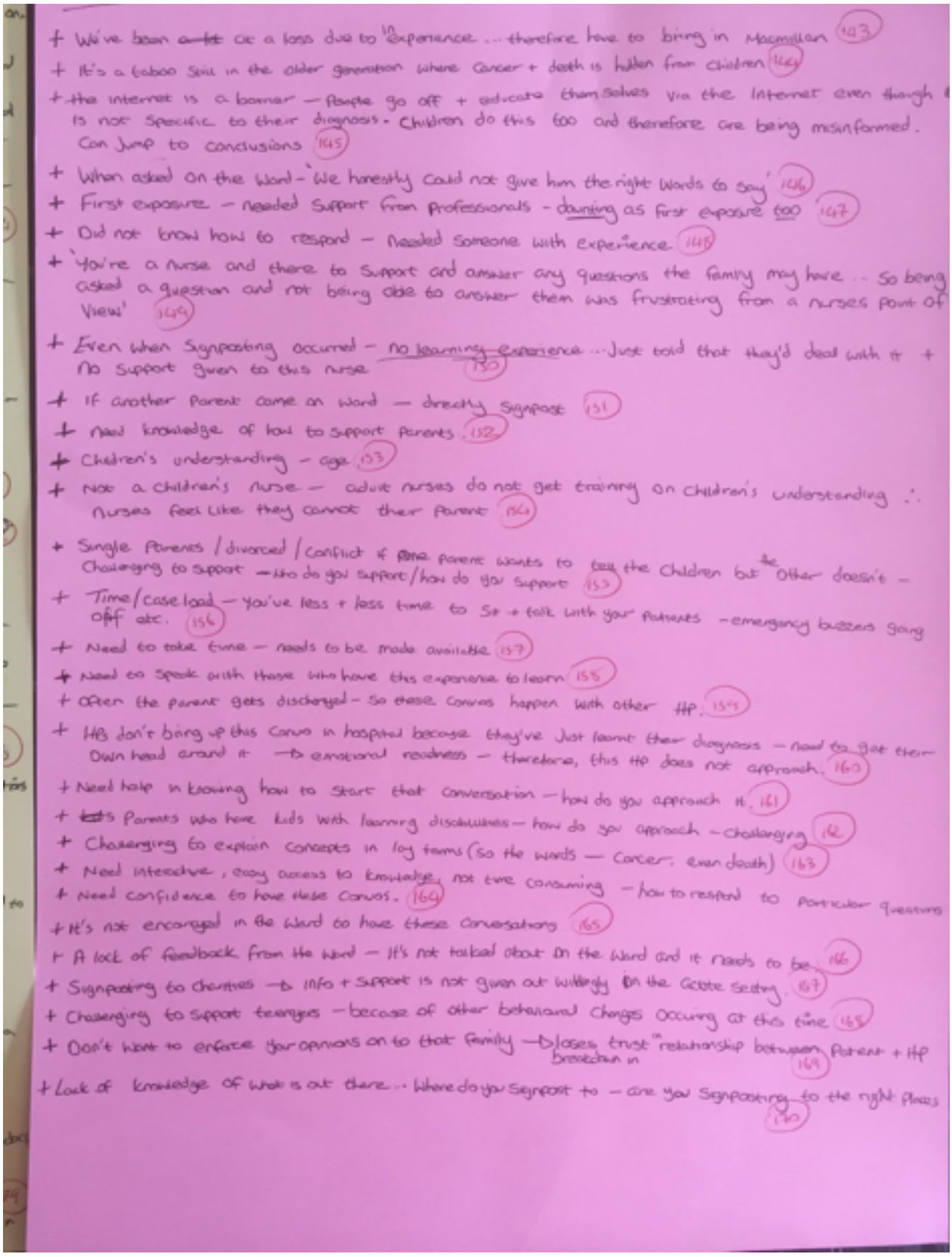
Record keeping:
The researcher will keep a record of when the Distress protocol has to be used and the actions taken and report this to the Chief Investigator.

Support for the researcher:
Throughout the study the researcher will have access to professional and management supervision

Management supervision: Professor Eilis McCaughan, Ulster University.

In addition as an Ulster University employee the researcher will have access to the Employee Assistance Programme (EAP). EAP offers confidential advice and counselling to help employees deal with a range of problems that might adversely affect their work performance. Available 24/7 it can be accessed by on Freephone 0800 389 5362 or by emailing support@carecallwellbeing.com. These services are provided by Carecall on behalf of the University.

Appendix V


+ We've been at a loss due to inexperience ... therefore have to bring in Macmillan 143
+ It's a taboo still in the older generation where cancer + death is hidden from children 144
+ the internet is a barrier — People go off + educate themselves via the internet even though it is not specific to their diagnosis - Children do this too and therefore are being misinformed. Can jump to conclusions 145
+ When asked on the ward - 'We honestly could not give him the right words to say' 146
+ First exposure — needed support from professionals - daunting as first exposure too 147
+ Did not know how to respond — Needed someone with experience 148
+ 'You're a nurse and there to support and answer any questions the family may have .. so being asked a question and not being able to answer them was frustrating from a nurses point of view' 149
+ Even when signposting occurred - no learning experience ... just told that they'd deal with it + no support given to this nurse 150
+ If another parent came on ward — directly signpost 151
+ Need knowledge of how to support parents 152
+ Children's understanding - age 153
+ Not a children's nurse — adult nurses do not get training on children's understanding ∴ nurses feel like they cannot their parent 154
+ Single Parents / divorced / conflict if one parent wants to tell the children but the other doesn't - Challenging to support — who do you support / how do you support 155
+ Time / Case load — you've less + less time to sit + talk with your patients - emergency buzzers going off etc. 156
+ Need to take time — needs to be made available 157
+ Need to speak with those who have this experience to learn 158
+ often the parent gets discharged - so these convos happen with other HP. 159
+ HP don't bring up this convo in hospital because they've just learnt their diagnosis — need to get their own head around it → emotional readiness — therefore, this HP does not approach. 160
+ Need help in knowing how to start that conversation — how do you approach it. 161
+ Parents who have kids with learning disabilities — how do you approach - challenging 162
+ Challenging to explain concepts in lay terms (so the words — cancer, even death) 163
+ Need interactive, easy access to knowledge, not time consuming — how to respond to particular questions 164
+ It's not encouraged in the ward to have these conversations 165
+ A lack of feedback from the ward — it's not talked about on the ward and it needs to be. 166
+ Signposting to charities → info + support is not given out willingly on the acute setting. 167
+ Challenging to support teenagers — because of other behavioural changes occuring at this time 168
+ Don't want to enforce your opinions on to that family → biases, trust in relationship between parent + HP breaches 169
+ Lack of knowledge of what is out there .. where do you signpost to — are you signposting to the right places 170

+ Some are diagnosed in the acute setting at the advanced stage – so the preparations are significantly advanced – not just informing the child of illness but also death – so it's fast. (171)
+ Parents are dealing with shock – ∴ emotional readiness is harder to achieve (172)
+ For those who are terminal → when is the time apart to have a conversation about telling the child they're dying – they don't know when the right time is. (173)
+ Some families have not told their children about the diagnosis full-stop – challenging, because it's trying to push them on to do/say so now – ∴ challenging to advise them because it's a conflict of interest (174)
+ Need to know how (from Professionals) how to respond to these situations (175)
+ Parents are afraid of frightening their children. Even though signposting + directing on – emotional readiness in accepting it from the parents' perspective. (176)
+ It's time consuming to overcome emotional readiness – takes a lot of time + trust to develop – some HPs don't have that time (177)
+ A good repair between the HP + patient (+ partner) is essential. – (178)
+ Trust is important – some HPs get those relationships and they need to take 'advantage' of that (179)
+ Being in acute oncology – is intense – everything happens incredibly fast (180)
+ When you are a CNS – they know who you are – they can see that you've knowledge – does this mean if you are just a ward nurse you don't? – they're not cancer specialists (181)
+ You don't want to push them into something they're not ready to do. – often it gets parked (182)
+ Every family + relationship is different – so what should I advise for them? (183)
+ Referring + signposting ... (184)
+ Communication is needed within the words + other teams – Big (185)
+ All rely on support from colleagues in talking about it – because it is challenging on them as HPs (186)
+ Referrals take too much time & you're leaving them in the dark for maybe 1-2 weeks – but don't have the knowledge & skills to do so (187)
+ Barrier – don't get follow-up with families or support services (188)
+ Teenage children – challenge – they are in room during consultations – you see the fear + distress – stages of being a teenager (189)
+ Starting point – 'what do you know' – (teenagers) (190)
+ Listen is important & give them time to talk (191)
+ Fear of doing the wrong thing – advising parents about their children – dangerous territory. (192)
+ books are available to signpost off to – but just looks like you don't know what you're doing (193)
+ Information is out there – but it's not in a collective place and therefore can't get access to (194)
+ Not having the answers to questions e.g. how long therefore how do you effectively support ... avoid conversations because don't know the answer to these questions. – ∴ treatment may prolong life. (195)
+ Really don't know what to say. (196)
+ Have avoided conversations due to a lack of confidence .– fear of saying wrong thing & bad then reacts (197)
+ Parents have their own ideas & you don't want to push them into something they don't ~~them~~ want to do (198)
+ Younger children – generally no idea on what words are right – Younger children are a challenge – other than saying 'be honest' – which is not enough. (199)
+ HP People hang on to everyword that is said to them – fear of saying the wrong thing. (200)
+ Sometime stepped convos & signposted because of being uncomfortable + fear of not directing in the right way. – lack of expertise (201)
+ Competing family interests – one wants to tell – another doesn't ... the wider family input + involvement (202)
+ Even when one family member does want to tell the other doesn't ... HP struggles in taking sides – fear of losing that repair. (203)
+ Trying to cling on for hope that we can get them home + manage symptoms – challenge – Are you taking that away for them? – not hope that you'll live but hope – some good times ahead & manage QoL for what is left. (206)
+ HPs struggle with the finality – knowing they are leaving that day and that's the end – you've built up relationship with the patient – so harder to support because it's almost a loss for the HP too. – makes you avoid these conversations (208)
+ Even with advanced communication skills – it's challenging (209)

Interview 01 – Reflections following transcription

Maybe a clearer instruction at the beginning of the interview that this is only about the kids

In areas where talked/asked about kids, he still steered convo.

Maybe out of cancer focus required – many parents gone through that service my report same – Rachel was great – but doesn't specifically tell us in what ways.

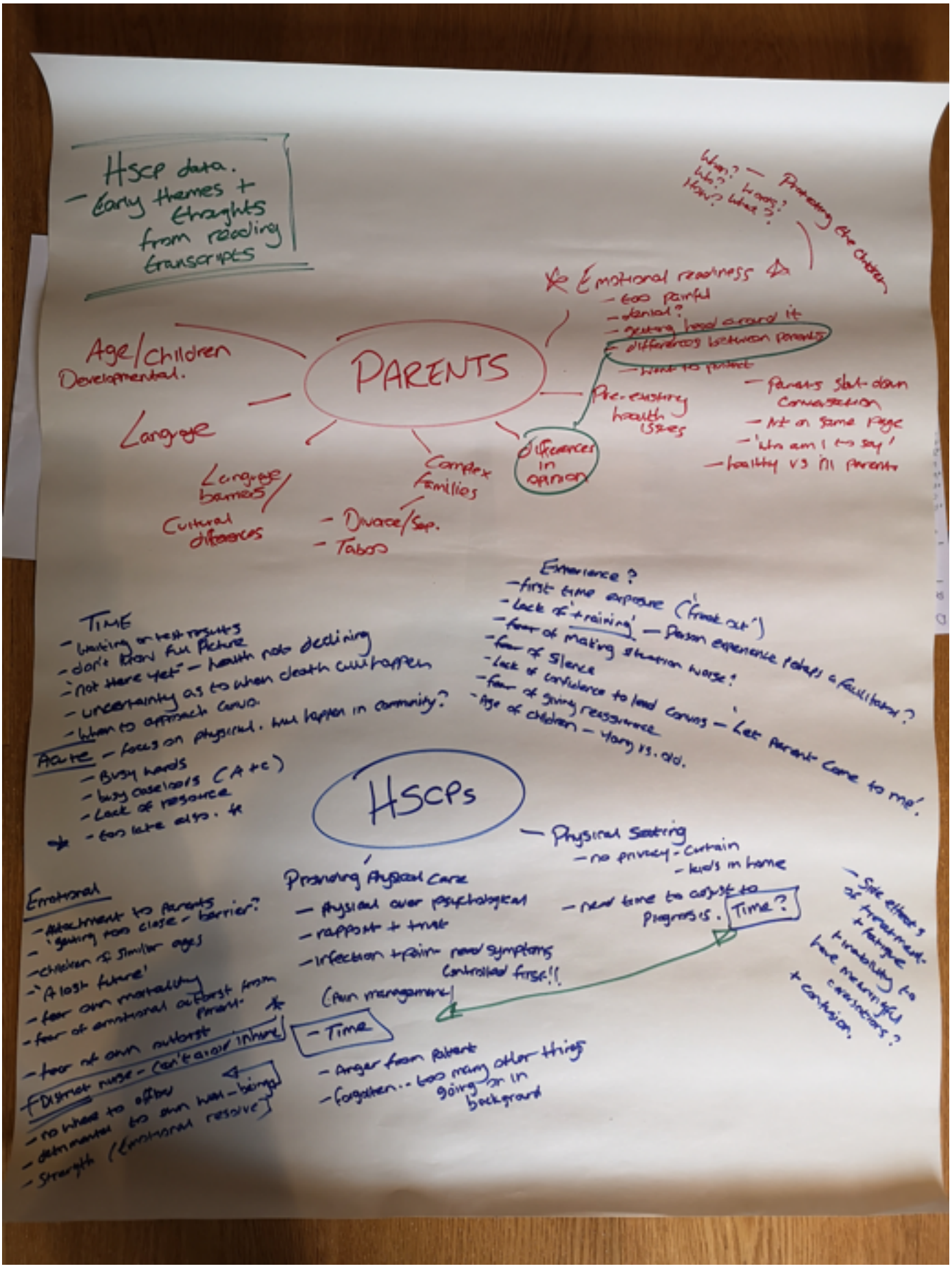
many places where he took over before question was asked so – getting q' clearer & concise.

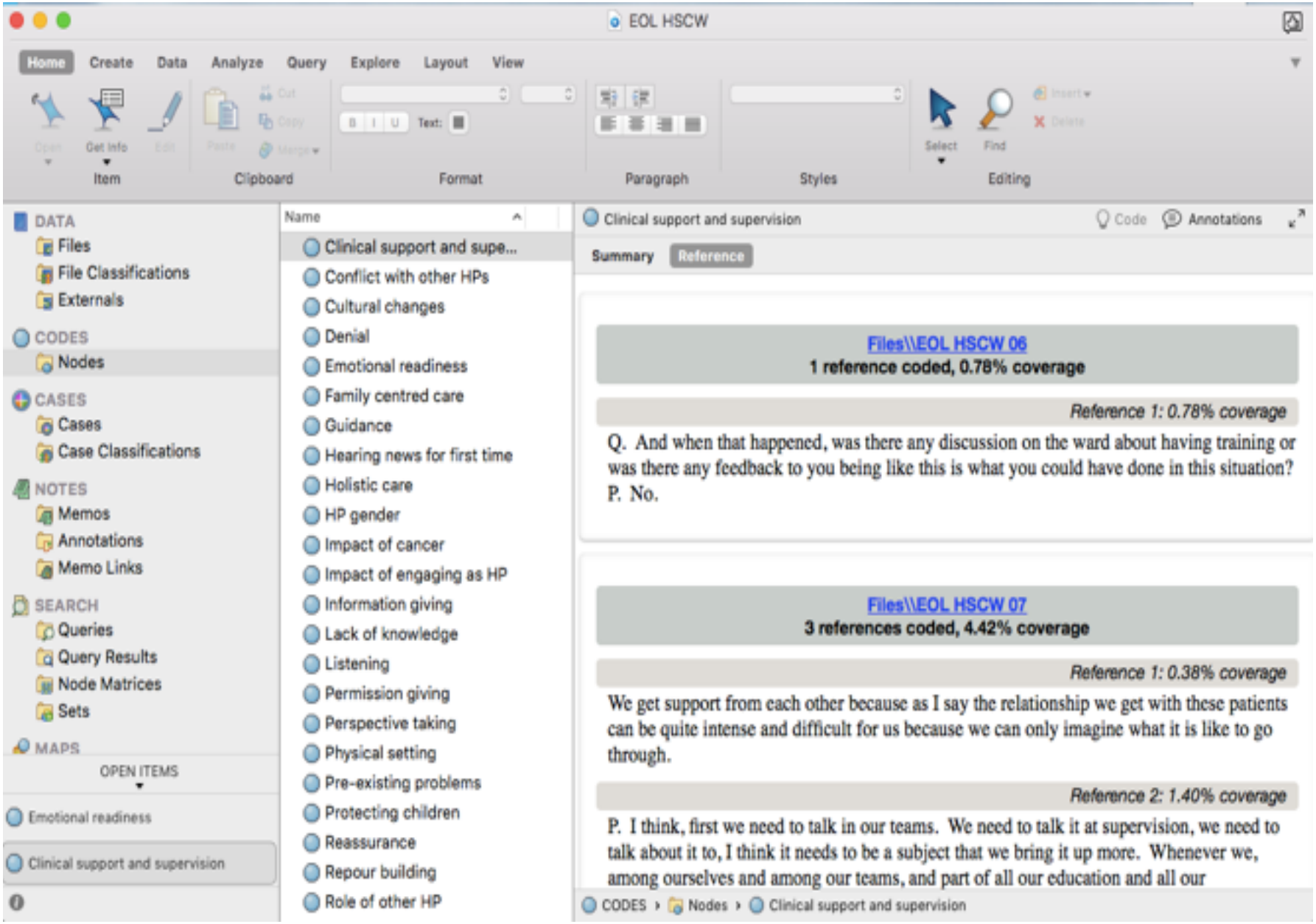
I get it's difficult to do but ex.

Some places have 2/3 things per question.

Maybe make it clear that there are many things going on such as finance, but we are here today specifically surrounding the kids needs & your needs in supporting them.

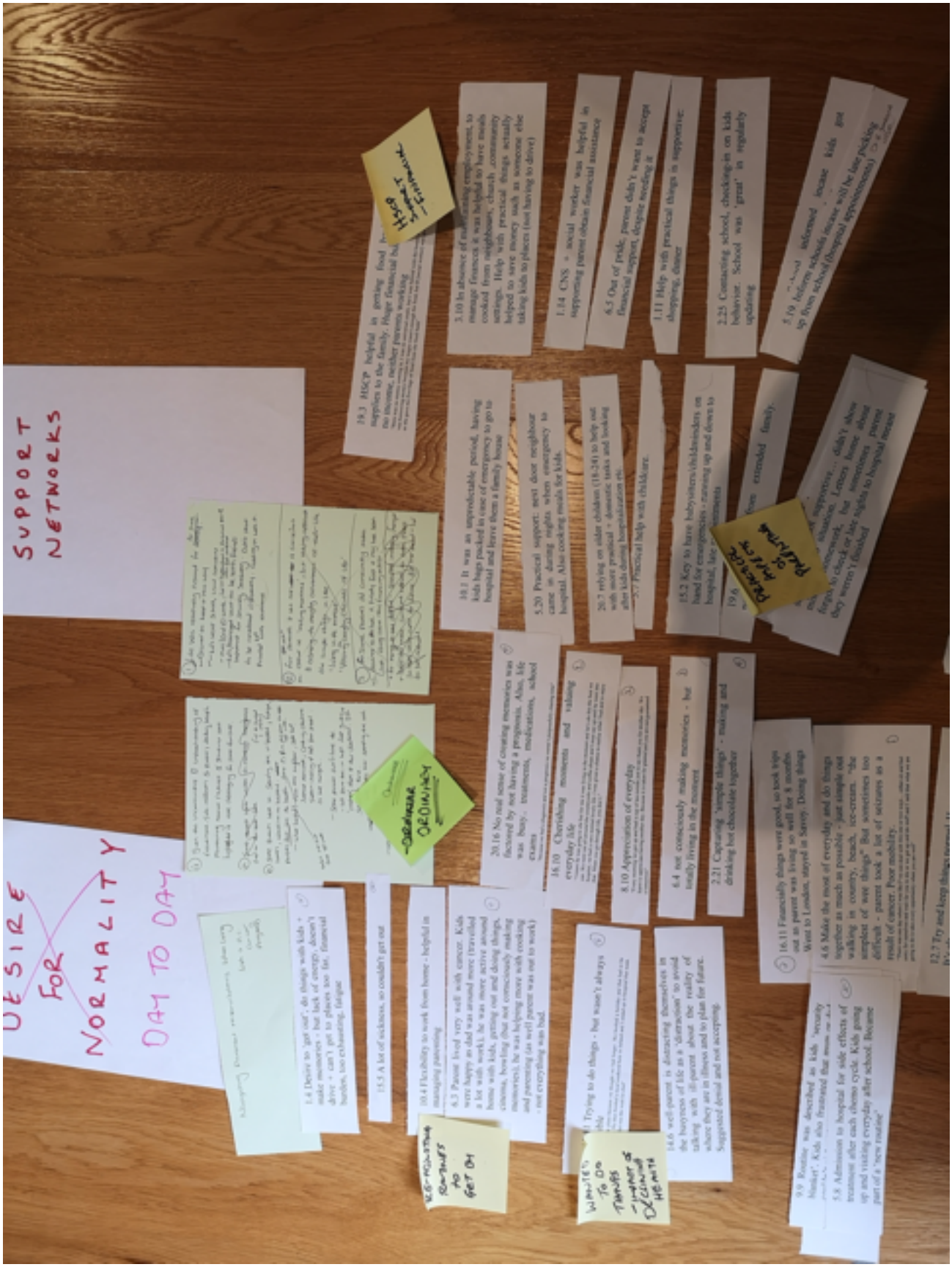
More convo around the end of life. – even if they aren't talking to the kids about it – maybe some q's over what they like – this was touched on with the dying & contact – but could go into other things

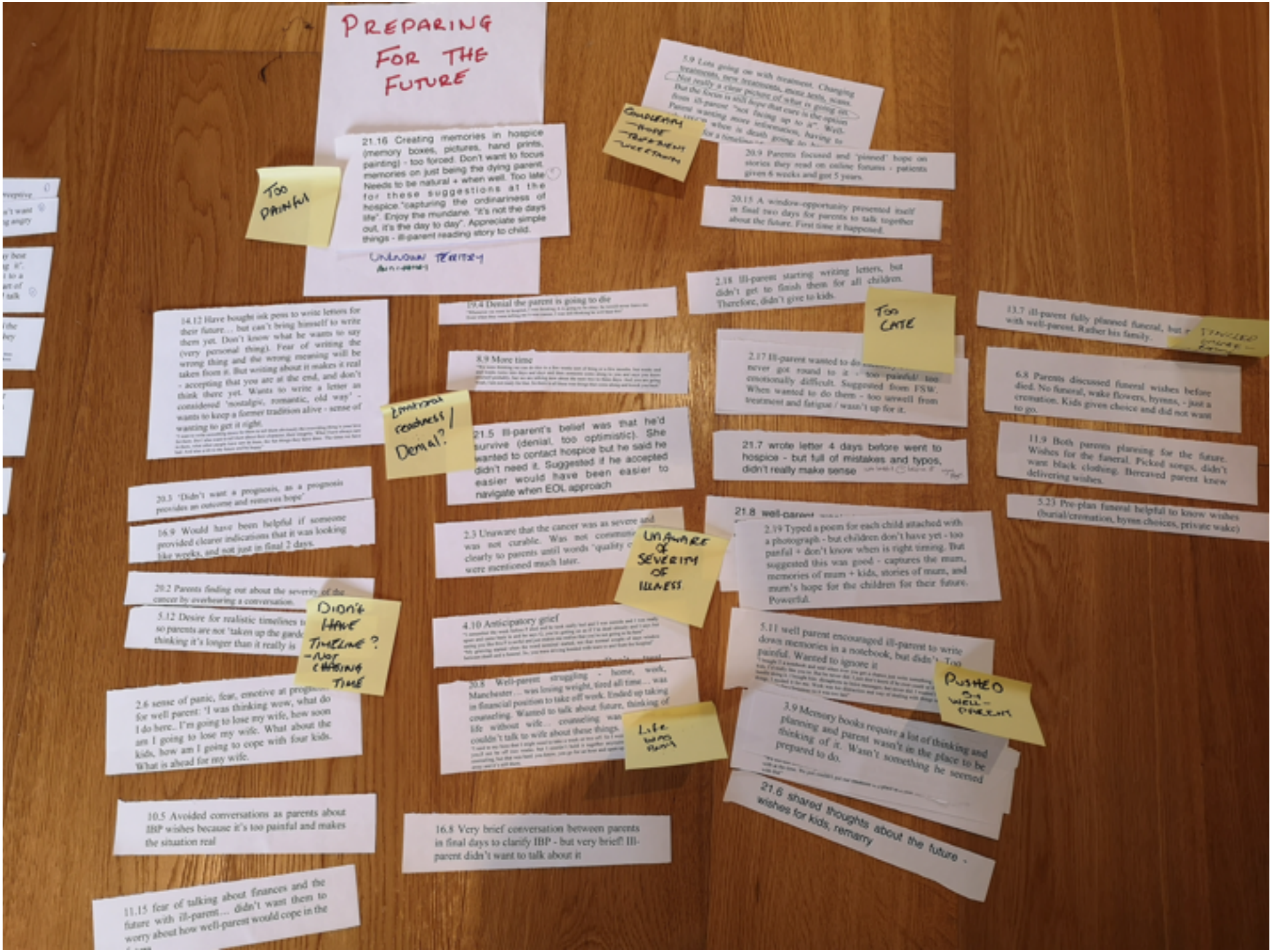

HSCP data.
– Early themes + thoughts from reading transcripts
PARENTS
Age/children Developmental.
Language
Language barriers/ Cultural differences
Complex families
– Divorce/Sep.
– Taboo
Differences in opinion
Pre-existing health issues
Emotional readiness
– too painful
– denial?
– getting head around it
– differences between parents
– want to protect
– Protecting the children
When? – Timing? Who? How? What?
– Parents shut-down conversation
– Not on same page
– 'who am I to say'
– healthy VS ill parents
TIME
– Waiting on test results
– don't know full picture
– "not there yet" – health rate declining
– uncertainty as to when death will happen
– when to approach carers
Acute – focus on physical. but happen in community?
– Busy wards
– busy caseloads (A+E)
– Lack of resource
– too late also. tt
Experience?
– first time exposure ('freak out')
– Lack of 'training' – Person experience pitfalls & facilitators?
– fear of making situation worse?
– fear of silence
– Lack of confidence to lead carers – 'Let Parent Care to me'
– fear of giving reassurance
– Age of children – young vs. old.
HSCPs
Providing Physical Care
– Physical over psychological
– rapport + trust
– Infection train- need symptoms Controlled first!!
(Pain management)
– Physical Setting
– no privacy - Curtain
– kids in home
– need time to adjust to Progress is. Time?
– Side effects of treatment + fatigue + inability to have meaningful conversations?
Emotional
– Attachment to Parents
– 'going too close' – barrier?
– children of similar ages
– "A big future"
– fear own mortality
– fear of emotional outburst from Parent
– fear of own outburst
– fear of own outburst in front of Parent nurse – Can't avoid in future
– no where to offer
– determined to own work – being strength (Emotional resolve)
– Time
– Anger from Parents
– forgotten.. too many other things going on in background

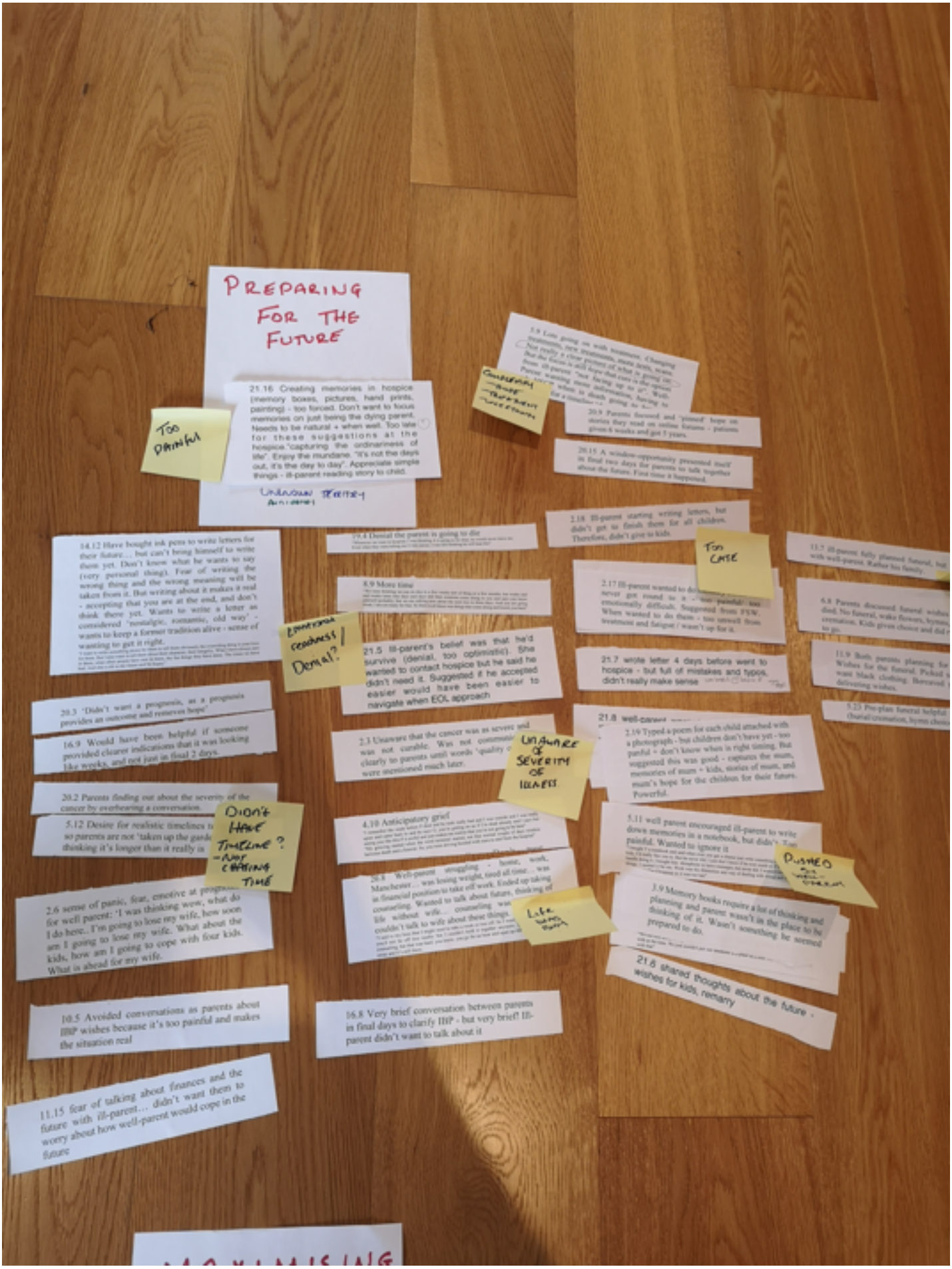

EOL HSCW
Home
Create
Data
Analyze
Query
Explore
Layout
View
Item
Clipboard
Format
Paragraph
Styles
Editing
DATA
Files
File Classifications
Externals
CODES
Nodes
CASES
Cases
Case Classifications
NOTES
Memos
Annotations
Memo Links
SEARCH
Queries
Query Results
Node Matrices
Sets
MAPS
OPEN ITEMS
Emotional readiness
Clinical support and supervision
Name
Clinical support and supe...
Conflict with other HPs
Cultural changes
Denial
Emotional readiness
Family centred care
Guidance
Hearing news for first time
Holistic care
HP gender
Impact of cancer
Impact of engaging as HP
Information giving
Lack of knowledge
Listening
Permission giving
Perspective taking
Physical setting
Pre-existing problems
Protecting children
Reassurance
Repour building
Role of other HP
Clinical support and supervision
Code
Annotations
Summary
Reference
Files\\EOL HSCW 06
1 reference coded, 0.78% coverage
Reference 1: 0.78% coverage
Q. And when that happened, was there any discussion on the ward about having training or was there any feedback to you being like this is what you could have done in this situation?
P. No.
Files\\EOL HSCW 07
3 references coded, 4.42% coverage
Reference 1: 0.38% coverage
We get support from each other because as I say the relationship we get with these patients can be quite intense and difficult for us because we can only imagine what it is like to go through.
Reference 2: 1.40% coverage
P. I think, first we need to talk in our teams. We need to talk it at supervision, we need to talk about it to, I think it needs to be a subject that we bring it up more. Whenever we, among ourselves and among our teams, and part of all our education and all our
CODES › Nodes › Clinical support and supervision

Appendix W

Appendix X




PREPARING FOR THE FUTURE
21.16 Creating memories in hospice (memory boxes, pictures, hand prints, painting) - too forced. Don't want to focus memories on just being the dying parent. Needs to be natural + when well. Too late for these suggestions at the hospice."capturing the ordinariness of life". Enjoy the mundane. "it's not the days out, it's the day to day". Appreciate simple things - ill-parent reading story to child.
TOO PAINFUL
5.9 Lots going on with treatment. Changing treatments, new treatments, many tests, scans. Not really a clear picture of what is going on. But the focus is still hope that cure is the opinion from ill-parent "not facing up to it". Well-Parent wanting more settlements, having to [illegible] whose is death going to be
20.9 Parents focused and 'pinned' hope on stories they read on online forums - patients given 6 weeks and got 5 years.
20.15 A window-opportunity presented itself in final two days for parents to talk together about the future. First time it happened.
14.12 Have bought ink pens to write letters for their future… but can't bring himself to write them yet. Don't know what he wants to say (very personal thing). Fear of writing the wrong thing and the wrong meaning will be taken from it. But writing about it makes it real - accepting that you are at the end, and don't think there yet. Wants to write a letter as considered 'nostalgic, romantic, old way' - wants to keep a former tradition alive - sense of wanting to get it right.
19.4 Denial the parent is going to die
2.18 Ill-parent starting writing letters, but didn't get to finish them for all children. Therefore, didn't give to kids.
TOO LATE
13.7 ill-parent fully planned funeral, but with well-parent. Rather his family.
8.9 More time
2.17 Ill-parent wanted to do never got round to it - too painful/ too emotionally difficult. Suggested from FSW. When wanted to do them - too unwell from treatment and fatigue / wasn't up for it.
6.8 Parents discussed funeral wishes before died. No funeral, wake flowers, hymns, - just a cremation. Kids given choice and did not want to go.
EMOTIONAL READINESS / Denial?
21.5 Ill-parent's belief was that he'd survive (denial, too optimistic). She wanted to contact hospice but he said he didn't need it. Suggested if he accepted easier would have been easier to navigate when EOL approach
21.7 wrote letter 4 days before went to hospice - but full of mistakes and typos, didn't really make sense
11.9 Both parents planning for the future. Wishes for the funeral. Picked songs, didn't want black clothing. Bereaved parent knew delivering wishes.
20.3 'Didn't want a prognosis, as a prognosis provides an outcome and removes hope'
16.9 Would have been helpful if someone provided clearer indications that it was looking like weeks, and not just in final 2 days.
2.3 Unaware that the cancer was as severe and was not curable. Was not communi clearly to parents until words "quality were mentioned much later.
UNAWARE OF SEVERITY OF ILLNESS
5.23 Pre-plan funeral helpful to know wishes (burial/cremation, hymn choices, private wake)
21.8 well-parent
2.19 Typed a poem for each child attached with a photograph - but children don't have yet - too painful + don't know when is right timing. But suggested this was good - captures the mum, memories of mum + kids, stories of mum, and mum's hope for the children for their future. Powerful.
20.2 Parents finding out about the severity of the cancer by overhearing a conversation.
5.12 Desire for realistic timelines so parents are not 'taken up the garde thinking it's longer than it really is
DIDN'T HAVE TIMELINE? - NOT CHASING TIME
4.10 Anticipatory grief
5.11 well parent encouraged ill-parent to write down memories in a notebook, but didn't. Too painful. Wanted to ignore it
PUSHED BY WELL-PARENT
2.6 sense of panic, fear, emotive at progn for well parent: 'I was thinking wow, what do I do here.. I'm going to lose my wife, how soon am I going to lose my wife. What about the kids, how am I going to cope with four kids. What is ahead for my wife.
20.8 Well-parent struggling - home, work, Manchester… was losing weight, tired all time… was in financial position to take off work. Ended up taking counseling. Wanted to talk about future, thinking of life without wife… counseling was couldn't talk to wife about these things.
LIE WAS RUN
3.9 Memory books require a lot of thinking and planning and parent wasn't in the place to be thinking of it. Wasn't something he seemed prepared to do.
21.6 shared thoughts about the future - wishes for kids, remarry
10.5 Avoided conversations as parents about IBP wishes because it's too painful and makes the situation real
16.8 Very brief conversation between parents in final days to clarify IBP - but very brief! Ill-parent didn't want to talk about it
11.15 fear of talking about finances and the future with ill-parent… didn't want them to worry about how well-parent would cope in the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19.4 Denial the parent is going to die
2.18 Ill-parent starting writing letters, but didn't get to finish them for all children. Therefore, didn't give to kids.
TOO CARE
11.7 Ill-parent fully planned funeral, but with well-parent. Rather his family.
8.9 More time
6.8 Parents discussed funeral wishes, died, No funeral, wake flowers, hymns, cremation. Kids given choice and did
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5.12 Desire for realistic timelines t so parents are not 'taken up the gard thinking it's longer than it really is
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UNAWARE OF SEVERITY OF ILLNESS
21.8 well-carer
2.19 Typed a poem for each child attached with a photograph - but children don't have yet - too painful - don't know when is right timing. But suggested this was good - captures the mum, memories of mum + kids, stories of mum, and mum's hope for the children for their futures. Powerful.
DIDN'T HAVE TIMELINE? - NOT CHASING TIME
4.10 Anticipatory grief
5.11 well parent encouraged ill-parent to write down memories in a notebook, but didn't. Too painful. Wanted to ignore it
PUSHED
20.8 Well-parent struggling - home, work, Manchester... was losing weight, tired all time... was in financial position to take off work. Ended up taking counseling. Wanted to talk about future, thinking of life without wife... counseling was couldn't talk to wife about these things.
LIKE
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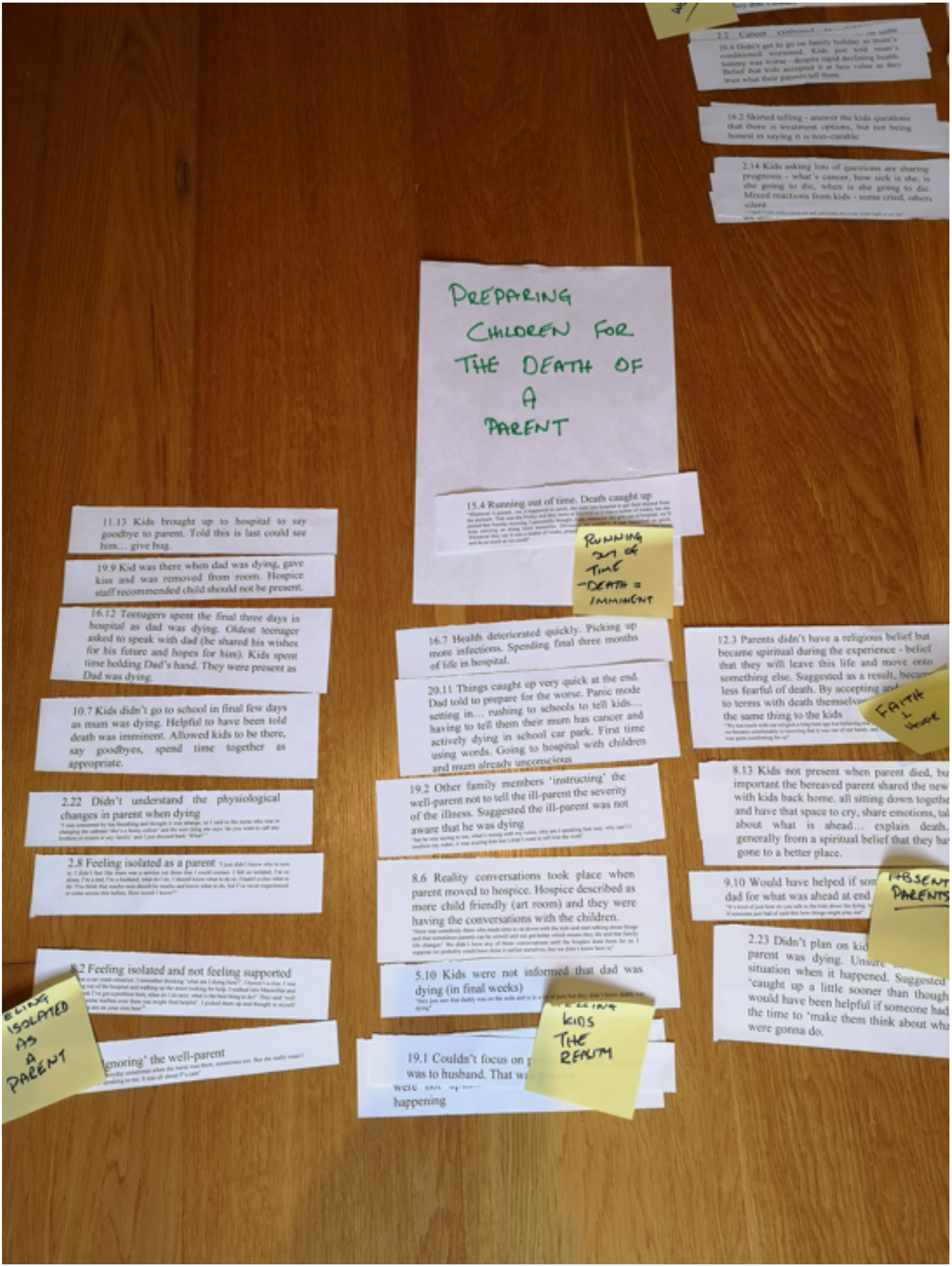
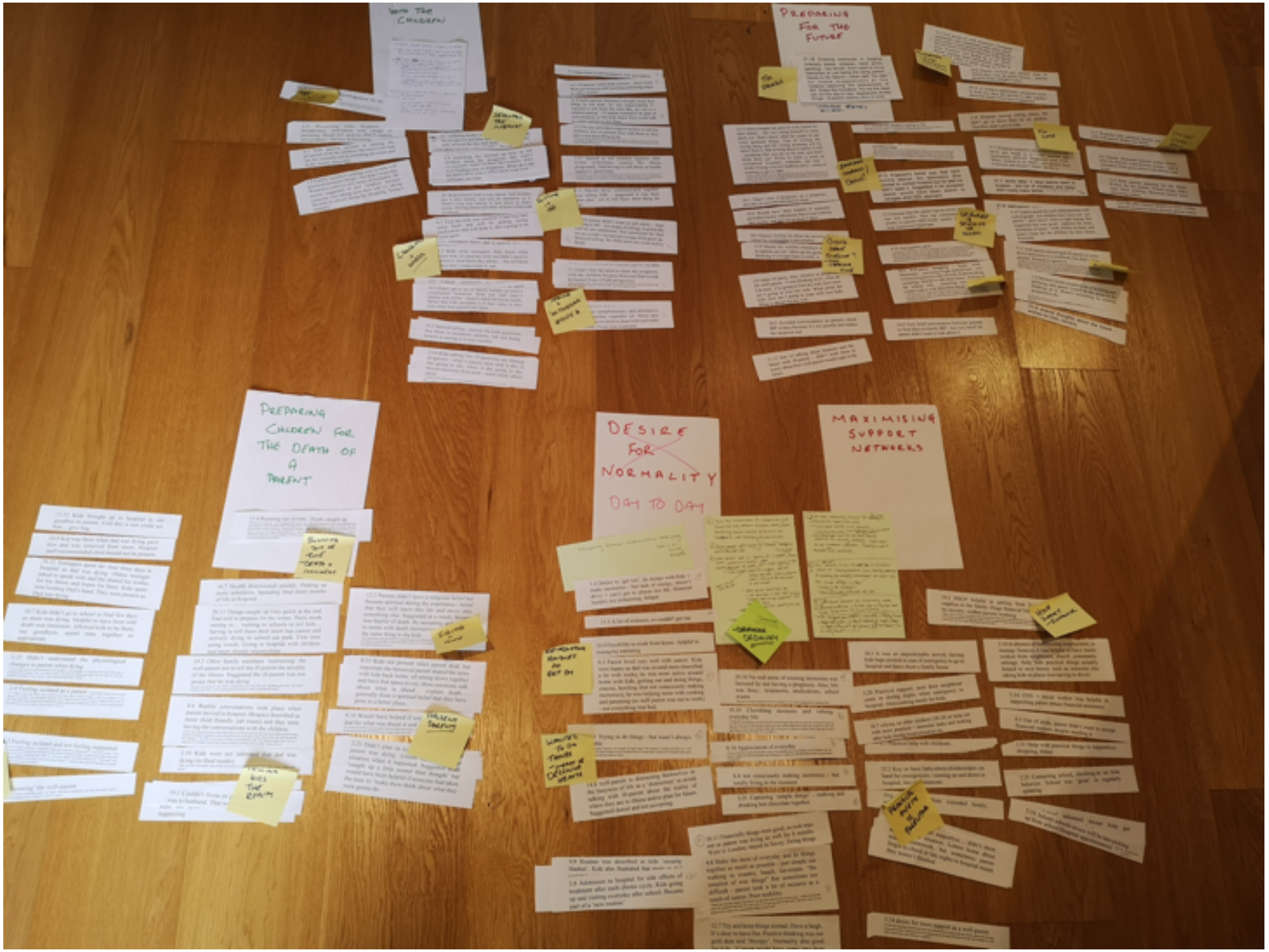

PREPARING CHILDREN FOR THE DEATH OF A PARENT
11.13 Kids brought up to hospital to say goodbye to parent. Told this is last could see him… give hug.
19.9 Kid was there when dad was dying, gave kiss and was removed from room. Hospice staff recommended child should not be present.
16.12 Teenagers spent the final three days in hospital as dad was dying. Oldest teenager asked to speak with dad (he shared his wishes for his future and hopes for him). Kids spent time holding Dad's hand. They were present as Dad was dying.
10.7 Kids didn't go to school in final few days as mum was dying. Helpful to have been told death was imminent. Allowed kids to be there, say goodbyes, spend time together as appropriate.
2.22 Didn't understand the physiological changes in parent when dying
2.8 Feeling isolated as a parent
8.2 Feeling isolated and not feeling supported
'ignoring' the well-parent
15.4 Running out of time. Death caught up
RUNNING OUT OF TIME - DEATH = IMMINENT
16.7 Health deteriorated quickly. Picking up more infections. Spending final three months of life in hospital.
20.11 Things caught up very quick at the end. Dad told to prepare for the worse. Panic mode setting in… rushing to schools to tell kids… having to tell them their mum has cancer and actively dying in school car park. First time using words. Going to hospital with children and mum already unconscious
19.2 Other family members 'instructing' the well-parent not to tell the ill-parent the severity of the illness. Suggested the ill-parent was not aware that he was dying
8.6 Reality conversations took place when parent moved to hospice. Hospice described as more child friendly (art room) and they were having the conversations with the children.
5.10 Kids were not informed that dad was dying (in final weeks)
19.1 Couldn't focus on p… was to husband. That w… were too upset… happening
KIDS THE REALM
12.3 Parents didn't have a religious belief but became spiritual during the experience - belief that they will leave this life and move onto something else. Suggested as a result, becam… less fearful of death. By accepting and… to terms with death themselves… the same thing to the kids
FAITH + HOPE
8.13 Kids not present when parent died, bu… important the bereaved parent shared the new… with kids back home. all sitting down togethe… and have that space to cry, share emotions, tal… about what is ahead… explain death, … generally from a spiritual belief that they ha… gone to a better place.
9.10 Would have helped if som… dad for what was ahead at end…
ABSENT PARENTS
2.23 Didn't plan on kid… parent was dying. Unsure… situation when it happened. Suggested … 'caught up a little sooner than though… would have been helpful if someone had… the time to 'make them think about wha… were gonna do.
ELINGS ISOLATED AS A PARENT


PREPARING FOR THE FUTURE
PREPARING CHILDREN FOR THE DEATH OF A PARENT
DESIRE FOR NORMALITY
DAY TO DAY
MAXIMISING SUPPORT NETWORKS

Diagnosis of Parent (incurable)

- Some parents are diagnosed as incurable
- Some had been on Curative pathways.

+ At this point, anticipatory grief.
+ Anxiousness.
+ knowledge that parent will not survive illness.
+ There is (in many cases) awareness death will be the outcome from the illness.
+ Shock of diagnosis
+ Pain + hurt in having to share the news with the children. The fear on how this will affect the children.
+ Many parents have clear understanding from HSCP that the cancer will not be curable. However, they are hopeful treatment may be effective. Looking for a cure.

Initial Sharing of News With kids

- Delays in telling the children
  - busyness of life - exams, School, birthdays, events

- Too soon; don't want to upset & cause pain + anxiety too soon
- hopeful for treatment to prolong life
- Denial + emotional readiness
- Lack of instructive HSCP support
- Lack of knowledge, understanding
- Lack of confidence.

- Sharing the news + the pre-existing roles in the family
  - many cases the news is shared by the more active parent & the parent who tends to make family decisions.

- Scavenging the internet
  - lack of HSCP support. Looking the internet for guidance. How do we do this

- In some cases, the initial Sharing of the news is rapid. When the parents health is rapidly decline - a matter of days in some parents cases.

- In some cases, while diagnosis may be shared with the children, the children are not informed that the cancer is incurable.

Here + Now (Parent)

- A strong sense of realisation that the Parent is not going to live past the illness & the 'living in the moment', cherishing moments.
- Spending more time together as a family.
- Games, holidays, trips away (last holiday)
- Capturing these memories in videos + photos.
- So the child will have these memories when the parent is gone.
- Some want to write, lettering for when gone - but delay. Too painful. Another time
- Realising what they have & more conscious effort to spend time together.

- While there is a lot of inside pain, hurt & anticipatory grief - this has to be parked.
  - busyness of life - kids have routine to be maintained. Going to School, homework, activities & clubs outside of school.
  - Bills to be paid. Work to be continued
  - looking after Ill-Parent

↓

- A lot of navigating, so the need to maximise social networks - need for help & support from family, friends, Church, neighbours to manage mundane life.

- Informing the School & ensuring the child's Progress is monitored. Regular updates from School if any changes to behaviour. Some kids given a pass to leave class.

- Hope - treatment may prolong life. Focusing + Still hoping for a cure, and clinical trials. Glimmer of hope that treatment will make life longer.

- No HSCP checking in on kids. Need for this & Providing realistic updates when health of Ill-Parent is declining

- Putting Plans in place. Financially. As much as possible. - Some have conversations about funeral arrangements, some shut it down - Painful. But has been helpful in the long run.

Here + Now (Child)

- as reported by parents.
- A need to be given updates
  - how are things progressing
- Regular updates

- Routine - school

Shifting Sand

① Living in the Moment and making the most of ordinariness. The joy of ordinary and being satisfied with what you can do. Liberation (see flipchart)

② Parallel beliefs – keeping home life, school routines, normality as relatively same. But there was intermitted glimpses of reality and insight into death approaching. (for few, these were brief moments). often featured by infections & declining health.

PTO
- You adapt & normalise.
- Illness becomes part of life

- Some never got there as it was too hard to confront death & reality that this was happening. Reality is, it's too hard to contemplate. ~~Starting to live is not going to be the same~~ ~~I don't want to be in this situation~~ Open communication as couple. don't want to upset. too painful don't want to close but don't know it.

③ Striving to live + not giving up (Hope)

RESISTANCE — I don't want to be in the situation I am in. focused hope on treatments that are currently available to extend life and hope that novel treatments or a long-lasting cure would be available. Hope

Religious — Hope was also Anned to faith. Not necessarily religious, but a spirited belief

Denial — Blind hope – this is not happening & resisting reality of the situation – Person will be cured / denial.

Acceptance — Hope also can be a positive thing, that suffering & joy can happen @ same time. pain that will die, but will live as best as possible until that moment happens.

④ ongoing communication & sharing with the Children. shared using pre-existing roles. But done so as & when they had emotional strength to do so
- need Emotional readiness to do so

myriad of strong powerful emotions.

overwhelmed + numb
Build strength up with the kids

Appendix Y

n the Mon... (see flipchart)

The news (Poor Prognosis) ...bstetric theory level.

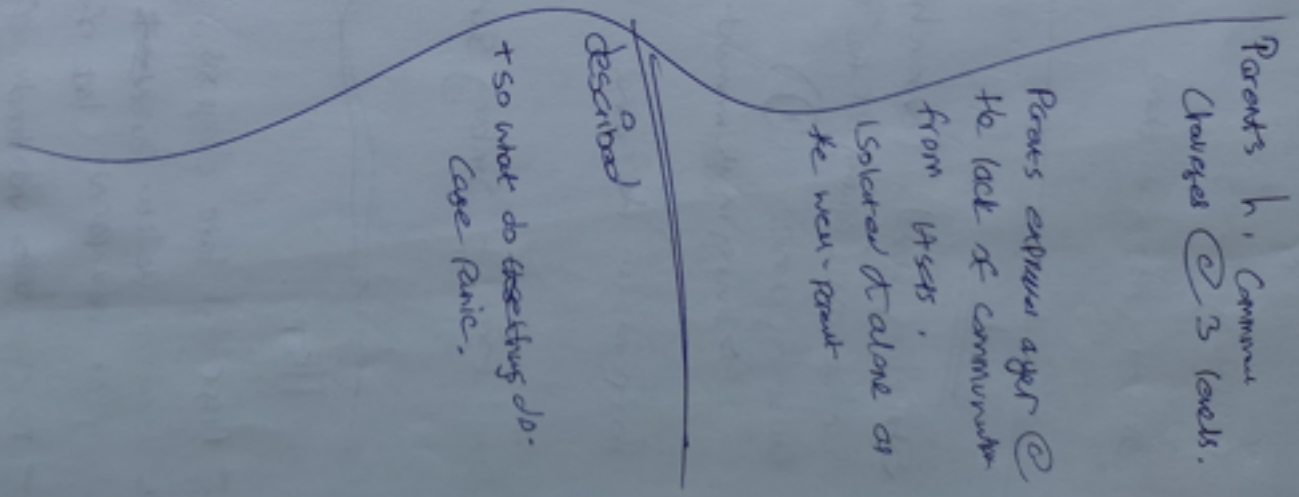
Focus of Paper: A journey Parents go through when a Parent is @ E...

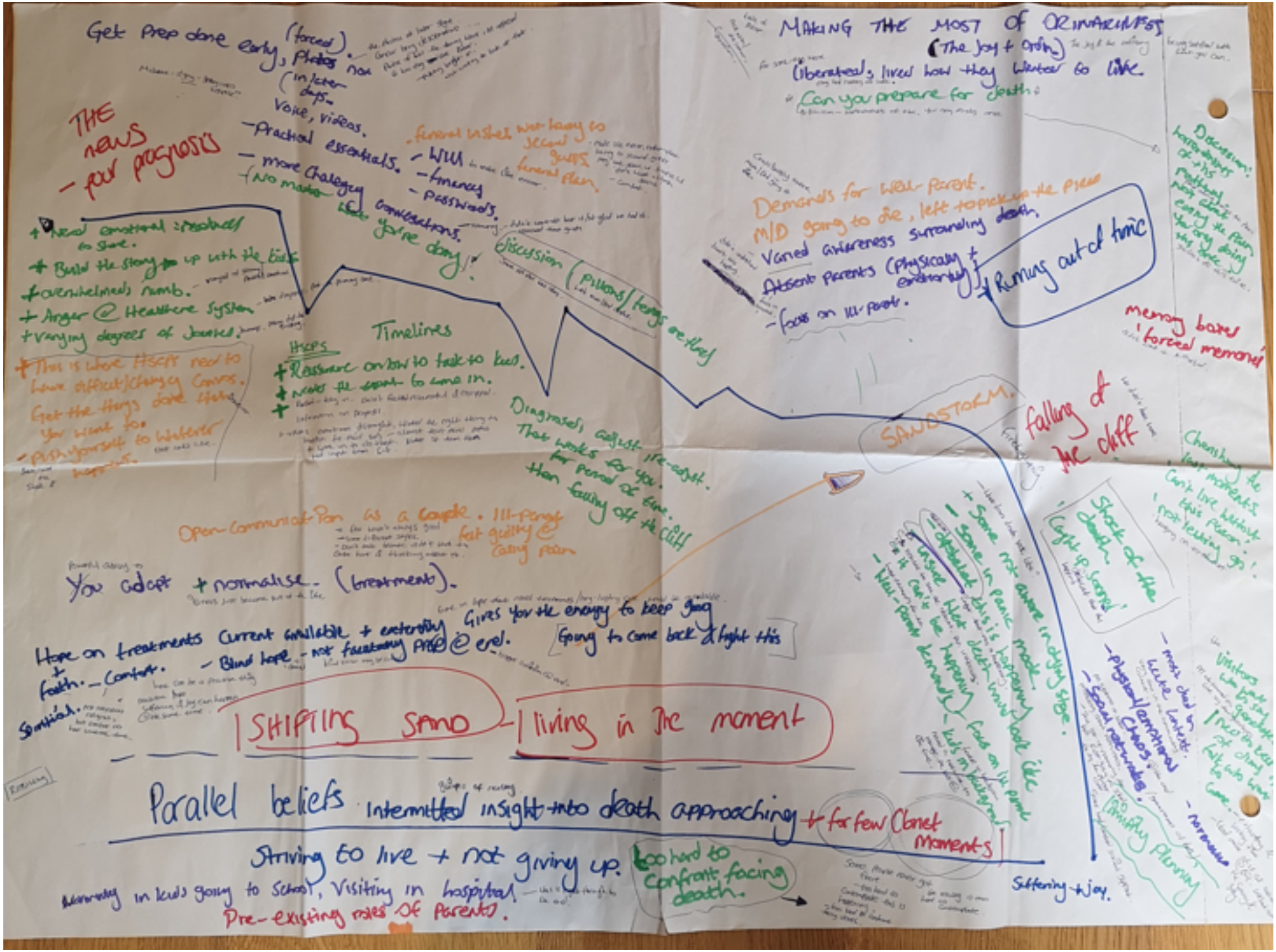
Making

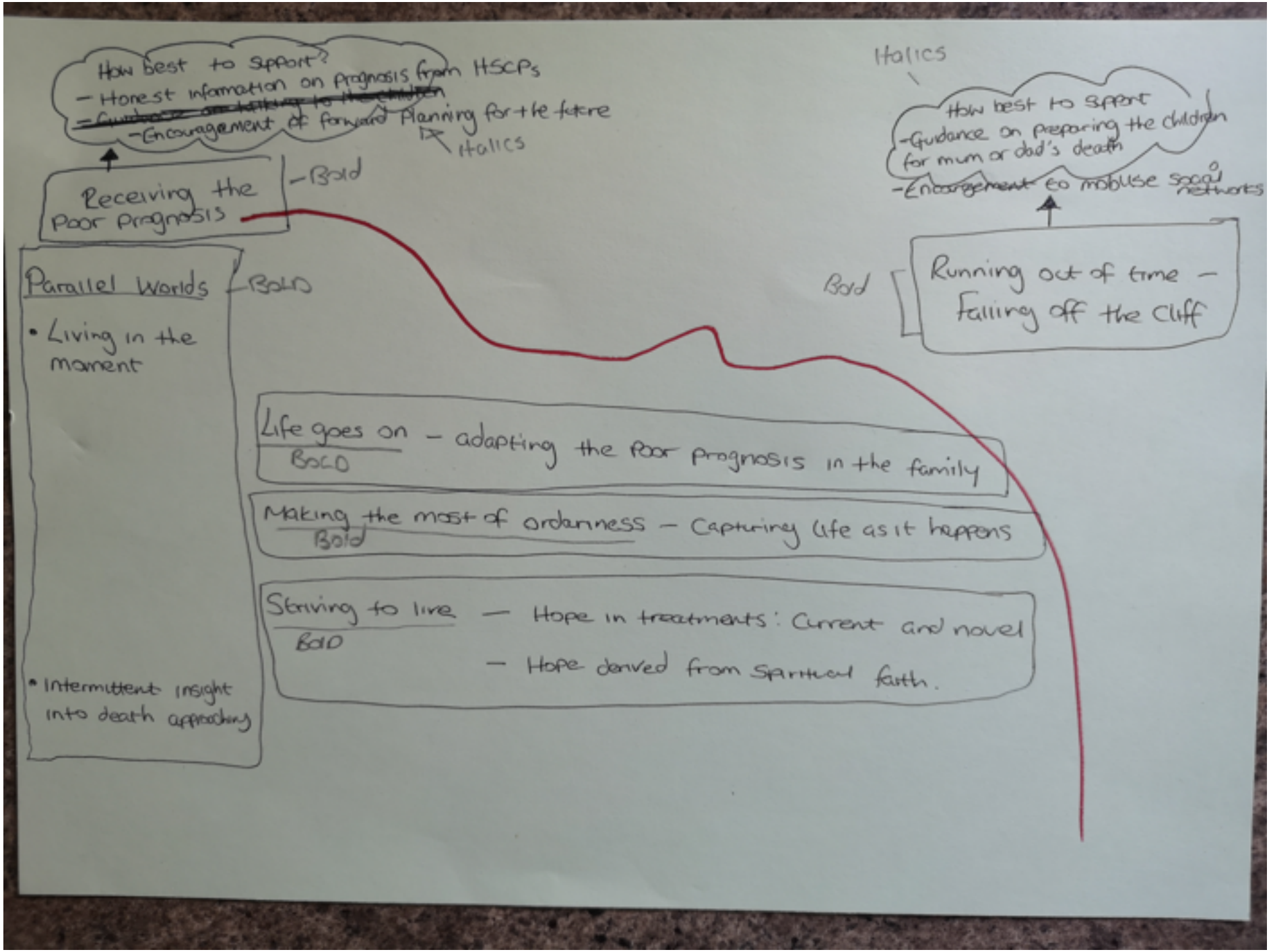
Two parallel tracks running @ the same time. Sense that we have to keep home life & everything going along, got kids and that's happening. But there was in the background & for a lot of ppl was pushed into the background that mum / dad is not well.

Sense of hope was very predominant in the hope that treatments were going to cure along & in around the individual's faith.

Then for the W- Parent, the striving to live & not giving up. Very powerful. Sense that I don't want to be in the situation him in & they were really working & taking on board




Get Prep done early, (forced).
Photos now (in later days.
Voice, videos.
Practical essentials.
more challenging conversations.
Funeral wishes
WILL
Finances
Passwords.
Funeral plans.
THE NEWS - POOR PROGNOSIS
+ Need emotional support to share.
+ Build the story up with the kids
+ Overwhelmed/numb.
+ Anger @ Healthcare System
+ varying degrees of Journey.
+ This is where HSCPs need to have difficult/challenging Convos.
Get the things done that you want to.
- Push yourself to whatever happens.
Timelines
HCPs
+ Reassure on how to talk to kids.
+ make the space to come in.
Discussion (Pillows) things are they
Diagnosed, called it re-edit. That works for you. for period of time. then falling off the cliff
MAKING THE MOST OF ORDINARINESS
(The joy + agony)
Liberated, lived how they wanted to live.
How can you prepare for death?
Demands for well parent.
M/D going to die, left to pick up the pieces
Varied awareness surrounding death.
Absent parents (physically + emotionally)
- focus on ill parent.
Running out of time
Discussion: happenings of this traditional pain chart carry the pain carry the story
Memory boxes / forced memories
SANDSTORM.
falling off the cliff
Chemo
Can't live without this person
Shock of the death.
Light up sparks
Open Communication as a Couple. Ill-person feel guilty @ causing pain
You adapt + normalise. (treatments).
Hope on treatments Current available + externally Gives you the energy to keep going
+ faith. - Comfort. - Blind hope - not functioning
Spiritual.
Going to come back & fight this
SHIFTING SAND
living in the moment
Parallel beliefs
Intermitted insight into death approaching + for few Closer Moments
Striving to live + not giving up.
Too hard to confront facing death.
Normality in kids going to school, visiting in hospital
Pre-existing roles of parents.
Suffering + joy.
Visitors
Practical Planning
Physical/emotional Chaos.
Social networks.
Future Contact.
Normality


How best to support?
- Honest information on prognosis from HSCPs
- Encouragement of forward Planning for the future
Italics
Receiving the Poor Prognosis
Bold
Italics
How best to support
-Guidance on preparing the children for mum or dad's death
-Encouragement to mobilise social networks
Bold
Running out of time - Falling off the Cliff
Parallel Worlds
Bold
• Living in the moment
• Intermittent insight into death approaching
Life goes on - adapting the Poor Prognosis in the family
Bold
Making the most of ordinariness - Capturing life as it happens
Bold
Striving to live - Hope in treatments: Current and novel
- Hope derived from Spiritual faith.
Bold

Appendix Z

Ulster University
Faculty of Life and Health Sciences
Record of Meeting between Research Student and Supervisor/s
(This form should be completed jointly by the research student and supervisor/s at the conclusion of each meeting)

1. Name of Research Student: JEFFREY HANNA
(BLOCK LETTERS)

Name of Supervisor/s: PROF. EILÍS MCCAUGHAN & DR. CHERITH SEMPLE
(BLOCK LETTERS)

2. Date of Meeting: 21/05/2018 **3. Duration of Meeting:** 100 minutes

4. Issues discussed (Please list)

- ✓ A discussion was held on the interviews conducted to date with both health professionals and bereaved parents. This was used as an opportunity to feedback the initial themes and data that are being generated from these interviews, including avenue's that are being explored and those to be explored.
- ✓ An update was discussed around the ethics medication and the governance meeting with the Hospice.
- ✓ A review of progression to date and revisiting the gant chart, mapping out work that has been done and ensuring adherence is being maintained to the schedule. A modification was applied to the gant chart.
- ✓ An update on training needs and assessment was discussed including NVivo training which has been completed since the last supervision.

5. Suggested further work (Please list)

- ✓ Setup the next health professional interviews. 6 have been identified to include 3 district nurses, 1 occupational therapist (community), 1 oncology physiotherapist (acute) and 1 acute care nurse.
- ✓ Make a revision to the topic guide/interview schedule as per the discussions that took place during supervision. Circulate back to team for review

- ✓ Revisit the systematic review. In advance of the next supervision - a re-run of the entire search must be completed and a new draft of the results section must be submitted up to one week in advance of the supervision

- ✓ Identify further bereaved parents to interview through the Bereavement Support Group and attending their memory walk next month

6. Are risk assessments for this project fully up to date: Yes ☒ **No** ☐

7. Date of next meeting: 25.06.2018

8. Signature of Research Student:

Signature of Supervisor/s:

Date: 23-05-2018